

# **Developing approaches to person-centred outcome measures for older people in rehabilitation settings**

**Lynne Corner**

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## Abstract

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The rationale for this study was the need to bring a social science perspective to developing approaches for person-centred outcome measures in rehabilitation settings for older people. To date this field has largely been dominated by clinicians and the biomedical model of impairment, disability and handicap. Qualitative methods (findings from focus group discussions informed later focus interviews with individuals) were used to establish and explore the views of older people about a range of issues linked to conceptualising outcome, including participating in decisions regarding their health, to examine how older people made judgements, what they valued and prioritised, what their expectations were, how care was experienced and how changes are sustained over time. Symbolic interactionism and grounded theory provided the overall theoretical approach to the methods used.

A distinction is made between older people's 'public' and 'private views'. This analytical distinction provides the framework within which the accounts are explored and presented in the thesis. The public accounts focus on the social and moral obligations associated with the experience of being an older citizen. The thesis explores the role of reciprocity, justice and conscience in these accounts. The private accounts reveal the wide range and diversity of opinion and experiences that exist. Three groups of people were identified: *empowered; reluctant collaborators; and dominated*.

It is argued that future best practice for outcome evaluation in health and social care professionals will need to explore the *private* views of older people in greater depth. Institutionalised ageism and structured dependency are major barriers to

empowering older people to participate in identifying outcomes. Until these issues are recognised and resolved, more meaningful participation in the identification and method of assessment of outcomes is unlikely. The findings should be of relevance to researchers, to users of health services and to clinicians working in rehabilitation settings for older people.

## Acknowledgements

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## Author's declaration

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Work for this thesis was undertaken while I was employed at the Centre for Health Services Research at the University of Newcastle. The design of the study, data collection, data analysis, including transcribing taped interviews and coding, was undertaken by myself.

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# Chapter 1

## An introduction to the problem of person-centred outcome measurement

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I wish to be an instrument of my own will, not other men's act of will ... I wish to be a subject, not an object ... deciding, not being decided for, self directed and not acted upon by external nature or by other men as if I was a thing, or an animal, or a slave incapable of playing a human role ... that is conceiving goals and policies on my own and realising them ... I wish to be a somebody not a nobody

(Isaiah Berlin, 1969, p14)

### Outcomes for whom?

Health status and health outcome measures are becoming increasingly important in order to assess the quality of care provided for patients (McColl *et al.* 1997; Bowling, 1996; Bowling, 1995). Traditional outcome measures used in research in rehabilitation settings for older people have tended to focus on rehabilitation, health intervention and outcome as an entity to be defined and quantified.

Normative approaches have dominated and the research methodologies which have accompanied the recent burgeoning of interest in outcome measurement have concentrated, with a few notable exceptions, and to a greater or lesser extent on deductive theorising. Whether qualitative or quantitative, the theoretical stance that has been adopted by researchers has involved aspects of hypothesis testing or *measurement*. This has tended to group people together into a common identity, based on particular narrow facets of living with chronic illness such as coping mechanisms, or ability to perform activities of daily living.

Outcome, then, has come to be differentiated by domains and activities, usually devised from the *professional's* perspective. By defining the tasks associated

with outcome, the frequency with which each task is performed, how long each task takes and whether additional help or support is received, it has been possible to identify how many people are doing what. Although this may provide a useful basis for the planning of services, based on the assumption that a certain level of intervention should be rewarded with a certain outcome, what most approaches leave out is any analysis of the *meaning and experience* of care. Until some of the conceptual problems surrounding the experiences of people receiving rehabilitation have been resolved, the precise value and meaning of these approaches can not be assessed. From a social science perspective, even if the treatment was the same for each person it would be difficult, given the nature of the socio-psychological processes of coping and adaptation, to measure outcome in this way. But for the past forty years we have tried to do precisely that using measures of impairment, disability and handicap. The picture that results from such studies presents a partial, incomplete and simplistic view of reality.

There is now an enormous array of questionnaires and interview schedules that have been developed to measure outcome (Bowling, 1996a; Bowling, 1995a; McDowell and Newell, 1987). Potential users, for example, can choose between measures developed for specific conditions (diabetes, asthma or arthritis) or more generic measures (Ware, Jr. and Sherbourne, 1992; McColl *et al.* 1997), between indices or profiles, or single item or multiple items. All standard texts on selecting and using these scales and instruments for measuring outcome have emphasised the fundamental psychometric criteria which these scales must meet. These include reliability, responsiveness, acceptability, feasibility, appropriateness and interpretability (Fitzpatrick *et al.* 1992; Fitzpatrick *et al.* 1998; McColl *et al.* 1997; Bowling, 1995; McDowell and Newell, 1987).



However, there is no language and framework for identifying what these terms mean to older people or how they may be discussed.

Another tenet of social science and of medical science is that the choice of research model is theory driven. In practical terms this means that the *choice* of outcome measures is influenced by existing theory or knowledge, including knowledge of person's perspectives, and by the objectives or hypotheses of the research. Yet we are so often driven to using inappropriate outcome measures because of current conventions and scientific fashions. By diktat we use certain measures in the name of standardisation and comparability, and often, inappropriately to the original intentions of the creators of the measures. Of course, there is little value in 'reinventing the wheel' and there is a lot of sense in using the same methods in order to allow for comparability between similar studies. However, there is a lot of 'self interest' in the selection of recommended outcome measures, scientists careers being dependent on success, and recommendations from powerful 'expert' groups who identify so-called consensus packages of outcome measures ensure that this basic tenet of social science is ignored.

A basic tenet of much social science is the perspective of the other (Mead, 1934; Blumer, 1969). In developing ways of measuring outcome the fundamental starting point is the identification of key stakeholders and a response to the question: outcomes for whom? Of course, the basis of medicine, like the political rhetoric of the NHS reforms is to put 'patients first'. Therefore, in developing measures of clinical outcome it will generally be the patient for whom the outcome measure is being generated. Yet, the selection and development of clinical outcome measures do not necessarily take the patient's perspective. In practice, most measures of clinical outcome are based on a professional view of

patient's outcomes; few measures have started from the point of inviting patients to identify the outcomes which they think are the most important.

## **Taking the perspective of an older person**

It is increasingly important to undertake evaluations which involve direct expression of views by users of health services. Only outcome measurement at the user and carer level can give a convincing indication of whether there is a good fit between needs and rehabilitation. This is complicated by the fact that there is a failure at a societal level to specify and achieve the standards of welfare which older people and their carers in the community should expect. Older people are not a homogenous group. It remains unclear what different older individual's expectations of services are. We know very little about what they would like services to achieve, both for themselves, and for others like them. We also know very little about their standards of comparison (frequently standards derive from a minimum standard).

Attempts to make outcome measures more 'person-centred' have been hampered by the lack of a model of 'normal' or 'successful' ageing, and researchers continue to make ageist, ethnocentric and sexist assumptions about what constitutes 'normal' life for people who are older. Further development in this area has also been hampered by a lack of definitional agreement and methodological inconsistencies between the various studies that have been done (see chapter 5). Conventional practice in the choice of particular outcome measures demonstrates a lack of satisfactory evidence to support the approaches taken. Unfounded assumptions often govern the type of approach taken and by focusing on the individual alone, the wider social, political and economic context in which individuals are situated is naively ignored. Despite a considerable body of emerging literature on the domains which constitute quality



of life (Farquhar, 1994; Farquhar, 1995; Bowling, 1995; Albrecht, 1994) the fact remains that we know far too little about the views and values that older people have. Older people's views are interpreted by researchers and clinicians within value-laden conceptual frameworks such as 'choice', 'participation', 'independence' and 'dignity' with older people rarely being asked directly to comment on what these concepts actually *mean*. Individuals are rarely asked to comment on the relevance and the relative importance of such concepts, and we have little data on if and how these might be interpreted and prioritised for different groups.

It is assumed that participation in health care planning is a 'good thing' (Long, 1996) and yet little weight is given to what older people make of being asked to take part in such a process. Whether the changes that have brought about this involvement are understood by a group of people who have been largely used to a paternalistic health service, and may be unaccustomed to having a say and be unaware that their views are wanted, are not included in discussions of these approaches. For example, individual's expectations may be dulled through exposure to traditional modes of service allocation.

Further work will be needed to establish whether a standardised approach to outcome measurement is possible, or whether it will always be necessary to examine individual's circumstances and experiences in detail. Different approaches may be needed depending upon the *purpose* of measurement. In particular, we do not know what dimensions older people think are important and are therefore worth exploring. We also do not know what older people think are the important outcomes of care.

Knowledge about people's different life histories, their life-styles, their expectations and different priorities is essential to discover what matters to

different groups of older people. It is only when we have this knowledge that we can begin to infer what the *value* of these outcome measures are to older people, how they *interpret* the scores and if they have any meaning.

## Aim and objectives of the thesis

The overall aim of this study is to explore and to obtain a better understanding of how older people conceptualise outcomes, from their perspective.

The choice of method for this study has been directly influenced by the perceived limitations of starting with ‘a’ theoretical analysis of outcome. It starts from the position that the significant perspective to adopt is that of the person, not different members of the multidisciplinary team.

This thesis challenges the current paradigm of outcome measurement in research in rehabilitation settings for older people. It is *not* the intention to produce a new outcome measure, and there is an important distinction between first *identifying* outcome and then *measuring* outcome (chapter 5).

The objectives of the study were as follows:

1. to establish and explore the experience of care from the perspective of the person and to try and understand how people articulate that experience;
2. to understand what older people’s expectations are, their knowledge and views of their condition and the meaning that their circumstances have for them;
3. to identify the factors which enable or the barriers which inhibit older people in defining desirable outcomes and in monitoring the impact of services
4. to develop strategies that researchers and health professionals might use to overcome these barriers

The key questions for the study are shown in Table 1.

**Table 1 Key questions for the study**

- how do older people conceptualise outcome?
- what factors are important in defining and examining outcome from the perspective of an older person?
- what are older people’s expectations, and do these influence how they conceptualise outcome?
- how and do they make judgements about effectiveness? Do they evaluate medical procedures? What do they attribute any change to?
- how feasible is it to adopt a standardised approach that allows for aggregation, as opposed to an approach that focuses on individual circumstances?

**The structure of the thesis**

For some people, injustices and inequities over the life cycle can be compounded in old age by poverty and ill health.

society creates the framework of institutions and rules within which the general problems of older people emerge, and indeed, are manufactured. Decisions are being taken everyday in the management of the economy and maintenance and development of social institutions, which govern the position which older people occupy in national life, and these also contribute powerfully to the public consciousness of different meanings of ageing and old age

(Townsend, 1981, p9)

In Chapter 2, the experience of growing older in contemporary society is considered. The main misconceptions and stereotypes of later life are highlighted. The view that older people are an homogenous group is challenged. Negative perceptions of older age and ageism are key themes. The stereotypes of older people and how they impact on an older person’s identity, self-concept and beliefs are discussed. The chapter continues with a discussion of the social meaning of growing older, and the way that older people’s lives can be limited by



the barriers in society. This can be through processes of legitimised and formal discrimination and also informal stigma. Structured dependency, then, is a key theme. Finally, the impact of how these negative images which effect the experience of older people in contemporary society have infiltrated rehabilitation settings and approaches within them are examined.

Chapter 3 examines the historical development and the changing context of the health care system in the UK, and how political changes have impacted on health professionals and their approaches to organising and managing care. A discussion of this is essential to a fuller understanding of the current emphasis on efficiency and effectiveness in the NHS. These developments, however, also give a crucial canvas to the prominence that has been given to consulting the public on health matters, both on an organisational and individual level. For example, the government directive 'Local Voices' gave purchasers advice on the different ways that they could involve the public in the purchasing process (NHS Executive, 1995). The rationale for this advice writes Bowling (1992) is that 'while experts within medical and health care specialities and professions can advise on clinical *facts* in priority setting, only members of the community can express community health *values*'. Patients are also encouraged to participate in health care planning on an individual level. Fundamental to this rhetoric is the notion that if patients are encouraged to participate in their care or rehabilitation then this will lead to focused and effective outcomes of relevance to the patient and those caring for them (Long, 1996). This may be a narrow, simplistic view as any evidence to suggest a direct link between participation and outcome is limited. In this thesis, these developments are considered in the context of conflicting perspectives - the humanistic and bureaucratic - in an attempt to illustrate the tensions and contradictions which arise between approaches which focus on the individual and the wider organisational structures.

Chapter 4 examines the shift in emphasis from cure to managing to chronic illness, and the social meaning of chronic illness. The impact and meaning of chronic illness in general on a person's physical, social and psychological functioning is considered, along with ways of coping. One of the characteristics of chronic illnesses is their clinical uncertainty - not only are they incurable, but often their specific manifestations are unpredictable and their progression and severity variable (Weiner, 1975; Charmaz, 1983). People with chronic illness, regardless of how well it is controlled, can still face both clinical and personal uncertainty about their condition. People with chronic illness are therefore dealing with a universal aspect of the human condition, but in an exaggerated form and with 'severely limited options' (Weiner, 1975, p102). The way in which chronic illness and disability fit within the WHO typology of chronic illness as impairment, disability and handicap is discussed. The medical and social models of disability are also explored, with particular reference to how these are relevant to older people in society, as individuals and as part of a wider group.

In chapter 5 the theoretical, methodological and practical issues in assessing outcome are discussed. Definitional difficulties in this arena are outlined and the competing perspectives are considered. 'Person or patient-centred outcome measure' is a short-hand term referring to 'the array of questionnaires, interview schedules and other related methods of assessing health, illness and benefits of health care interventions from the patient's perspective' (Fitzpatrick *et al.* 1998). It is increasingly recognised that traditional biomedically defined outcomes need to be complemented by approaches that focus on the person's concerns in order to evaluate interventions and identify more appropriate forms of health care. Interest in this area has been fuelled by the increased importance of managing chronic conditions and the focus on maintenance rather than improvement alone (chapter 4). The focus on biological ageing, the medicalisation of old age and



the dominant medical paradigm of the way that services and the whole approach to older people are organised is indicative of a status quo that is deeply engrained in the social psyche.

There are also issues in terms of implementing outcome measures in routine practice as opposed to research settings. It is unclear how broad principles, such as the promotion of independence, may be translated into measurable form, or how their measurement could be combined with aspects of outcomes that may only be applicable to some users.

The impact of services is an important consideration. If it is possible to determine which aspects of outcome are important to all users and which are relevant to some, then once the possible domains have been identified, experimental work might build on models which allow users to select those domains which are important to them. Similarly, in distinguishing between the outcomes of some health and social care services, an inter-agency approach may often be desirable. So, if boundaries are unimportant to users, then this might be an incentive for this to take place. In setting out to assess the psychosocial functioning of older people, we are concerned, essentially, with measuring what has come to be referred to variously as their 'quality of life' or 'health related quality of life'. In other words, we are concerned with investigating the impact of their condition and the proposed treatment on the non-clinical aspects of their functioning. However, there is no consensus about what these terms actually mean and there is a tendency for the terms to be used interchangeably.

Chapters 6 to 9 describe the rationale for the methods used in the study and describe the processes of data collection and analysis. The findings from a



series of focus groups held are discussed in chapter 10, while descriptive data from the focus interviews are presented in chapters 11 to 15.

In chapter 16 the broad findings from the study are summarised. It will be argued that older people as a group are oppressed and discriminated against in wider society, and in the health care system. Because of this, meaningful participation in care is difficult and this impacts on how they conceptualise quality of life. These factors influence how researchers identify and evaluate outcomes in rehabilitation settings. Recommendations for the study of outcomes for older people in rehabilitation settings in the future are made, and a way forward suggested.

## Chapter 2

### Growing older in contemporary society

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An unfortunate trend in recent years has been the increasing tendency to depict the growing numbers of older people in the population as a problem

(Coleman and Bond, 1990)

#### Ageing in society

Ageing is universal, in that it effects all members of the population, and is progressive in that it is a continuous process. Biological models illustrate that ageing is intrinsic as most living organisms show an age-related decline in functional performance, and it is therefore inevitable and degenerative: the one certainty is that we will die. However, *society* has constructed ageing using such biological and medical models to support the view that *all* individuals follow a similar trajectory from birth to death, leading to the view that 'all people over 65 are old'.

One of the main misconceptions of later life is that chronological age determines biological, sociological and psychological ageing. Negative stereotypes about later life dominate. Older people are treated as a homogenous group, masking great diversity in the ageing process, which is hugely complex. This chapter discusses how this view of ageing has arisen, and explores the predominantly negative perceptions of old age and stereotypes which are inherent in this. It also examines how these images and stereotypes effect the experience of

growing older in contemporary society, and finally, how these values have infiltrated rehabilitation settings and approaches to examining outcomes.

## **Demographic trends**

The demographic trend in the UK, in common with other European countries, indeed with countries worldwide, is increased longevity as a result of downward trends in infant mortality rates and fertility rates (OPCS, 1993). The two World Wars also influenced the birth rate . Each war was followed by an increase in the birth rate and subsequent increases, for example in the mid-60s and mid-80s, can be traced to the post-war cohort of female children reaching child bearing age (Bond and Bond, 1994). Changes in the economic and social structure have mediated this cohort effect. For example, changes in family size, earlier marriage and many women delaying conception led to a stabilising of the birth rate in European countries (Bond and Bond, 1994). Once the size of any birth cohort is known the prediction of the size and structure of the adult population is a relatively straightforward calculation, although it is by no means an exact science, and mortality and migration remain important factors. For example, we do not know what changes in lifestyle (for example, smoking) and environment will occur in the twenty-first century which will influence mortality rates (for example, the epidemiology of AIDS) and the subsequent changes in the demographic structure of societies. However, it remains important to try and project the structure of future populations as the planning of health, welfare and social security provision requires this data. Yet, despite the fact that the ageing of the population in the UK has been evident for much of this century, it is only in the last two decades that the implications of an ageing population have been taken seriously by planners and policy makers (Coleman and Bond, 1993). The nature of political processes often means that any considerations are short term



and often short sighted. An unfortunate trend is that dramatic terms such as 'burden' and 'impending crisis' are characteristic of the predominant perspective used by policy makers and health and social service planners when discussing the growing number of older people in the population (Coleman and Bond, 1993) and concerns about the increasing dependency ratio and the economic pressures that are expected to accompany this are widespread.

Although current theories of human ageing predict that life expectancy is unlikely to increase much beyond present levels (Featherstone and Hepworth, 1993), the expectation of life is forecast to continue to rise into the next century (Bond and Bond, 1994). The most significant trend in population for the United Kingdom is the differential changes among age bands, with an increase in the number of people of very advanced age. While there is no denying the challenges that professionals face in providing health and social services for the growing number of frail older people, or indeed the poor quality of life (see chapter 5 for further discussion of this concept) experienced by many older individuals (Townsend, 1981), it is disappointing that the positive aspects of old age at the end of the twentieth century are not promoted with such energy (Coleman and Bond, 1993).

Increases in the life expectancy of older people in the second half of the twentieth century reflect improvements in quality of life, and to a limited extent some of the achievements of medical science. However, the role of medical or biological science is over-emphasised and future improvements in health and life expectancy are likely to come, as in the past, from changes in the *physical and social environment* rather than from improved treatment of diseases once they have occurred (McKeown and Cross, 1969). Joseph (1990) and Scrutton (1990) believe that society is far too inclined to concentrate on the 'problems' of old age. Bond (1993) also agrees that viewing old age as a problem perpetuates ageism. From a social model, it is the social disadvantage that people suffer that creates

problems, not the individuals themselves. Critical gerontologists and social constructionists have attacked the medical model and problem-oriented approach (Mulley, 1994) for promoting a 'victim blaming' approach, looking for the problems within older people rather than in society (Norman, 1987; Kenwood, 1990). So, we are led to believe that older people are isolated or suffer from hypothermia because of their age, rather than because of their low incomes or poor housing conditions.

### ***Gender differences***

Another important feature of human ageing is the greater longevity of women than men. Arber and Ginn have shown that 'in comparing a 65 year old in 1906 and 1985 a man can now expect to live for another 13 years, instead of 11, but a woman can expect to live another 17 years instead of 12' (Arber and Ginn, 1990, p9). This imbalance of the number of men and women has a number of consequences, particularly in terms of marital status and living arrangements (Coleman and Bond, 1993). There is a tendency for men to marry women younger than themselves, and due to increased longevity, women are more likely to experience widowhood. Also, women are less likely to remarry than men and so more older women live alone.

## **Attitudes to old age**

### **Institutionalised ageism**

Society's dominant stereotype of later life is one of frailty and dependency. Butler (1975) suggests that the concept of ageism is socially produced, defining it as a process of systematic discrimination and stereotyping of people, simply because of their age. Similarly, Hawker (1985) defines ageism as society's negative and patronising attitudes towards its older members, which reinforces the suggestion that the concept is socially, as opposed to biologically defined. Of



course, no age group is exempt from age-discrimination, but older people are affected by ageist attitudes more than any other age group (French, 1997).

Stereotypes are a way of presenting a one-sided, exaggerated, and normally prejudiced view of a group of people (Abercrombie *et al.* 1988) - gross over-generalisations which simplify reality. Stereotyping is a social psychological process in which negative attributes that may in fact exist in only a small percentage of older people who are frail and dependent are taken to be a general attributes of *all* older people. Stereotyping can lead to discrimination - 'the unequal treatment of individuals or groups based on arbitrary characteristics' (Reber, 1985). Discrimination is the behavioural component of prejudice (French, 1997). These concepts are key, as they form the theoretical basis to understanding ageism. This discrimination may take the form of older people being denied access to employment, leisure activities, education and medical treatment simply because of their age.

### **Ageist images in society**

Images of ageing are significant in contributing to our understanding of the position of older people in society. Ageism manifests itself in a culture in a number of ways. Both in the popular and academic literature and in the media (for example, television advertising) ageist images pervade. These images are not merely through stereotypes of 'an older person', but also through promotions which encourage people to 'look younger', 'or stay young looking' implying that to appear older has negative connotations and that only youth is valued. Also, charities portray older people as pathetic and dependent (Norman, 1987). Johnson and Wolinsky (1993) believe that in this context such negative images are used to raise public awareness of their disadvantaged position, but such a portrayal tends to reinforce negative perceptions of older people.



### ***The impact of retirement***

Ageism is also prevalent in the structures of society, firmly embedded in the practices of institutions and reflected in government policy (French, 1997). The fact that people are forced to retire at a given chronological age, whatever their wishes or abilities may be, is another example of the inflexibility of ageist practices and the way that retirement fosters ageist stereotypes (Laczko and Phillipson, 1990). The words 'retire' and 'retirement' foster an image of decline. Cumming and Henry's (1961) now discredited theory of 'disengagement' helped foster this negative image of voluntary withdrawal and retreat. The activities of older people tend not to decline if they stay in good health and have an adequate income (French, 1997); the barriers in the environment limit full social activities rather than the individual's themselves.

There is a large sociological literature on retirement which has been a major focus for research and debate in social gerontology. This debate largely focuses on the social and psychological theories surrounding the impact of retirement upon both individuals and groups. In the 1950's, with the dominance of 'role theory' retirement was seen by gerontologists less as causing 'problems' because of its financial implications, rather than because of the reduction in status and self esteem and the loss of work based friendships. However, by the 1970's other theoretical models were beginning to challenge the assumptions of role theory and the discredited 'disengagement theories'. These approaches emphasised the impact of class, gender and race in influencing the experience of retirement - in short, retirement came to be seen as 'socially constructed', varying according to lifelong social status and prevailing socio-political factors which influence and control retirement outcomes (Fennell *et al.* 1988). A further important factor here is that people's attitudes and their responses to research questions are framed within a social and political context.

Financially, older people are denied many of the benefits to which younger people are entitled, such as disability living allowances and are forced into poverty and dependency by low pensions and the spurious notion that they need less money than younger people (Walker, 1990), despite no firm evidence for this. Lack of wealth reduces social standing and personal resources, thus their dependency and status are socially constructed, at least in part. This is not to imply that all older people are poor; their personal resources and their social standing within society are likely to mirror earlier stages of their lives (Bond, 1993).

Ageist policy reflects the capitalist society in which we live which emphasises youth, energy and technological innovation. People who are economically inactive are devalued and perceived as a burden to the capitalist state. The social goods they have to offer, such as companionship and unpaid labour, especially in terms of informal caring, are largely disregarded (Bond and Coleman, 1993).

For all these reasons researchers continue to view retirement in a negative light. Another factor, is the fact that retirement is an area over which most people have little direct control and the post-retirement lifestyle is perceived as a predominantly negative one. However, this assumes that it is work that forms a persons identity, when equally it could be other factors for different individuals:

.... each person has several roles that he stakes his identity on. Work may be at or near the top, but not necessarily so. There simply is not the kind of homogenous consensus on the value of work that would keep it at the top for everyone. In fact, the many systems of competing values in a complex society ensure that there will be a wide variety of self-values. Thus the probability that retirement will lead to a complete identity breakdown is light, and there may be just as many people who rely on leisure pursuits for self respect as there are those who rely on work, particularly among those with unsatisfying jobs

(Atchley, 1977, p16)



Gender differences in adjustment to retirement have been reported by a number of researchers. But perhaps the most important theme which is emerging from the sociological literature on retirement concerns the relationship between retirement and other phases in the life course. This emphasises how an individual adjusts to retirement in the context of their own life history and the wider social structure.

### ***Ageist language***

Ageism frequently operates through language (Barbato and Feezel, 1987; Thompson, 1993). It is not trivial to focus on this: attitudes are reflected in the language we use and are shaped by the language we hear (French, 1997). People refer to older people in terms which older people may find patronising and embarrassing (Knowles, 1987). Terms of endearment used by relative strangers (such as 'Granny' or 'pet-lamb') can be demeaning (Payne, 1989), especially when the stranger has power over the person and the older person is expected to address them formally. Such terms can serve to infantilise older people. The word 'geriatric' is used as a noun (Norman, 1987), and many euphemisms are used to replace the word 'old', such as 'pensioners' or 'senior citizens'. Older people are citizens like everyone else (Croft and Beresford, 1991).

Terms such as 'the elderly' and 'the aged' can also be criticised for fostering the impression that older people form a homogenous group (e.g. Help the Aged), whereas in reality they are as heterogeneous and diverse as any section of the population, even in terms of age, which may span 30 - 40 years. Such terms are often used in medical literature and journals. Similarly, Wertheimer (1988) and French (1994) criticise such terms as 'the disabled' and 'the handicapped'. Wertheimer (1988) questions the use of the term 'care' as it fosters a negatively dependent and helpless image which is often inappropriate. Yet, the term 'Care of the Elderly' has now been adopted in favour of 'geriatrics' in many hospitals

nationally, which ironically is, in essence, a neutral term - referring to a medical speciality like 'paediatrics' or 'orthopaedics'. The term has taken on a derogatory quality because of negative attitudes towards older people in society (French, 1997).

Older women are in a particularly difficult situation:

Suffering from the double burden of ageism and sexism, older women have for too long been marginalised by society at large and by the literature stemming from sociology, gerontology and feminism: their visibility invariably restricted to the portrayal of negative stereotypes  
(Fennell *et al.* 1988)

Older people from ethnic minorities also suffer multiple oppression, and stereotyped views which include that they always belong to an extended family network which is ever ready to help and support them (McCalman, 1990).

Ageism interacts with sexism, racism, and disablism. Thompson (1993) believes that 'anti-ageism needs to be part of the wider enterprise and challenge of anti-discriminatory practice'.

Terms such as 'you can't teach an old dog new tricks' are examples of the erroneous belief that older people are incapable of learning new skills, a view hotly disputed by Ellard (1988). Similarly, the term 'senile' as a prefix for 'dementia' is also ageist as 'senile' merely means 'relating to or belonging to age'.

## **Misconceptions of later life**

Although it is true that illness and impairment are concentrated among older people more than any other age group, deterioration of health is not inevitable as we age and the majority of older people remain independent and healthy.

Thompson (1993) contends that the extent of illness and disability in old age is grossly exaggerated, and yet genuine symptoms can be disregarded, by health



professionals and older people themselves, as an inevitable consequence of old age. These ideas may be reinforced by the fact that health workers are in contact with a disproportionate number of older people who are ill and disabled (Marshall, 1990). The differences between old and younger people have been exaggerated; there is no medical condition exclusive to old age (Johnson and Wolinsky, 1993; French, 1997) and most older people never need long-term institutional care (Bond, 1993). Indeed, only 5% of older people live in an institutional setting (Bond, 1992).

Another misconception is that most old people suffer from dementia (Jorm, 1990). According to Joseph (1990), 29% of people over 80 years of age show some signs of dementia, but although this is a sizeable minority, it does leave 71% free of the condition. 80% of people over the age of 85 are not mentally frail (Bond, 1993). Depression is the most common mental illness in old age, as it is for younger people, but it is frequently confused with dementia, especially as depression can be a major cause of forgetfulness. Given the social conditions in which older people live, loss of employment, less resources, loss of spouse or friends, depression can often be explained in terms unrelated to biological ageing (French, 1997). Dementia should not be regarded as part of the 'normal' ageing process (Hasler, 1989) - the dementias are a group of illnesses of different causes (Davison and Neale, 1990) and people can have signs of confusion due to, for example, high temperatures, lack of fluids, poor nutrition or as a side-effect of medication.

It is often assumed that older people are physically isolated, yet in reality only about 20% of people over the age of 65 live alone, and they might choose to do so, as people from any other group might. It is also wrong to equate living alone with loneliness (Thompson, 1993), and to equate loneliness with social isolation.

A further erroneous notion is that older people are unproductive and a burden on society. This can be used as an excuse to limit or not provide services and for giving preferential treatment to younger people (Thompson, 1993). Yet, older people form the back-bone of informal care. Successful older people are generally thought to be the exceptions, which reinforces society's ageist attitudes.

Some decline in intelligence, as measured by intelligence tests has been demonstrated in older age, but according to Gross (1993) and Ellard (1988) this is mainly due to a reduced memory span and a slower rate of response. Any lessening of such abilities is not necessarily important in everyday life and is probably compensated for in most situations by an increase in experience and knowledge.

In really advanced age the negative effects of biological ageing upon psychological functioning may be more evident than the benefits of experience, but for the greater part of the life course, the gains are likely to be as evident as the losses

(Bond *et al.* 1993)

There is also a danger of viewing any changes which may occur in old age as necessarily negative.

Another common belief about older people is that they have inflexible personalities, although there is evidence to support the fact that there is no sharp discontinuity of personality with age (Joseph, 1990; Coleman and Bond, 1993) and again there are as many different personalities among older people as there are among any other age group (Felstein, 1990). The life-experience of a person will influence how they behave, along with their attitudes and views in later life. Also, people's behaviour is likely to be influenced not only by personality characteristics, but by the situations they are in (French, 1997). A common stereotype is that older people talk of the past - this may be because the present



offers so few opportunities. But younger people also talk of the past, it is just that the past is more recent.

## **A self fulfilling prophecy**

Perhaps the most unfortunate outcome of ageism is the effect it may have on the self-concept, beliefs and behaviour of older people (Marshall, 1990; Coleman and Bond, 1993).

Older people themselves act in ways expected of them and so collude in a social construction of reality in which society sets them apart and they in turn expect and accept that they are a group apart

(Joseph, 1990)

This process, whereby oppression is internalised leading to low self-esteem, has been termed the 'self-fulfilling prophecy' (French, 1997). Many older people may believe or accept societies stereotypic ideas about them, just as members of any oppressed group might before consciousness raising occurs (French, 1997).

Thus, they may delay seeking medical advice because they perceive their symptoms as the inevitable consequence of old age, they may feel 'grateful' for their bus-passes, whereas advice from the Disability Rights Movement would prefer this to be viewed as only necessary because pensions are inadequate.

Older people may believe that younger people are 'more important' than they are, and this may be reflected in their lesser demands on health and social care services. Such beliefs can alter the behaviour of older people, and confirms the stereotype and justifies negative attitudes. Ageism, sometimes like other types of discrimination (for example, sexism), is perpetuated and propagated by people who will themselves someday be old. People participating in ageism are thus contributing to their own eventual victimisation. Older people must contend with cultural stereotypes that not only devalue them socially but that teach them to devalue themselves, repeating the cultural mantra of ageism taught to them by the media and confirmed in their interpersonal experiences.

Even if individual's do not share these beliefs and attitudes, to challenge stereotypes requires determination, courage and stamina. For example, in a hospital setting, if people refuse to conform to hospital routine, this may have negative effects for them (Waterworth and Luker, 1990). In many ways, the role of an 'old person' is forced upon them by society, and their behaviour in this role only serves to reinforce ageist beliefs and to justify ageist practices.

### **Ageist attitudes in rehabilitation settings**

Many health professionals are working with older people in both hospital and community settings. They represent the interests of older people and so it is vital that any ageist attitudes are challenged to ensure that communication and practices are effective. It is important therefore, French argues, with reference to physiotherapists, that they acquire a knowledge and experience of older people who are well (French, 1997) as by constantly interacting with people who are ill and disabled, their views of older people in general will be distorted. She contends that:

physiotherapists are in a position to reduce ageist practices in their work places. This can be achieved by offering old people choice, attempting to 'improve' the environment, involving older people in decision-making regarding their rehabilitation, and challenging the overall running of institutions and community services

(French, 1997)

She offers no way, however, that this can become reality as opposed to well-meaning rhetoric, arguing that current structures serve only to relieve professionals of the demanding task of viewing and relating to people as individuals (French, 1997).

Research has increasingly tried to reflect the needs of older people. However, these interests are often not at the conceptual level and so well-intentioned



interventions can miss the mark due to artificially simplifying complex concepts. An important theoretical step forward in advancing the study of ageism and our understanding of old age is to reconceptualize the phenomenon in terms of the experiences and understanding of those who are older. Developing a theoretical understanding of the meaning of ageing allows one to begin conceptualising ageism in a manner that reflects the interests and experience of older people, clearing the way for the design of interventions that speak directly to their concerns.

Stevenson (1991) believes that a huge educational programme is necessary to combat negative attitudes towards old age among health professionals. Day (1988) argues that health professionals should take every opportunity to challenge ageist attitudes in older people themselves. Thompson (1993) suggests that is part of the health professional's role to give old people positive feedback to enhance their self esteem. However, many papers are patronising and paternalistic in content and tone, and few have sought to address issues such as ageism, and issues such as participation in health care from the perspective of older people themselves, or offer practical solutions as to how ageist attitudes and practices might be eliminated.

## Summary

Contemporary society marginalises and discriminates against older people. Although older age can be perceived in terms of economic and political processes, it has usually been viewed in terms of biology and psychology, and most of the literature on ageing has taken a *medical* perspective where the problems of old age are *individualised*. There is a tendency to view problems experienced by older peoples as 'individual problems' and to ignore their basis in historical, cultural and social structures. The focus is on the individual, the older

person tends to be 'blamed' for their problems, in spite of the broader contexts that structure them. The next chapter examines the position of older people in the changing context of the health care system.

## **Chapter 3**

### **The changing context of the health care system**

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society creates the framework of institutions and rules within which the general problems of the elderly emerge, and indeed, are manufactured. Decisions are being taken everyday in the management of the economy and maintenance and development of social institutions which govern the position which the elderly occupy in national life and these who contribute powerfully to the public consciousness of different meanings of ageing and old age

(Townsend, 1981, p9)

Over the last decades, there have been widespread changes in the structure and management of the NHS, and in health care (Royal College of Physicians and British Geriatric Society, 1992; Long, 1994). This has been accompanied by conscious attempts by government to shift power from the medical profession and to the introduction of managers, purchasers and providers. Government policy (NHS Executive, 1995) emphasises the perspective of the individual, of the consumer, the patient. This has been accompanied by the expectation that users of health and social care services should be involved in decisions about how we judge the efficiency and effectiveness of services within a democratic system. The development of health care technologies has out-paced resources to fund these technologies. This is by no means a recent development; even five years after the establishment of the NHS, expectations exceeded availability (Maxwell, 1995). The scarcity of resources has fuelled an ongoing debate as to if and how these resources should be rationed. As a response to that, for example, prescriptions were introduced, as a disincentive to consume scarce



resources. This section first explores the key issues around rationing in the NHS and considers how rationing underpins ageism.

Increasingly, organisational issues about how to make health care more efficient have gained prominence and this has included the concept of involving consumers more directly in the organisational structure of the NHS. This section also explores what is meant by lay participation in health care. Fundamental to the rhetoric is the notion that if patients are encouraged to participate in their care or rehabilitation then this will lead to focused and effective outcomes of relevance to the patient and those caring for them. This may be a simplistic view as participation is a complex concept and there is not necessarily such a direct link between participation and outcome. A discussion of the changing context of the health care system is essential to a fuller understanding of the emphasis on outcome in the NHS.

## **The rationing debate**

Health care rationing is not a new concept to the NHS: it has in fact been part of the system since the NHS began (Maxwell, 1995). In the past, however, from the inception of the NHS, rationing was implicit, an exercise left for doctors to do behind closed doors (for example, waiting lists, clinical decisions etc.).

Doctors are less shocked by rationing than is the public. They have been at it for years

(Cochrane *et al.* 1991, p1561)

Implicit rationing served the purposes of deferring awkward problems. In today's NHS however, with its new managerial structures, there is less willingness 'to leave decisions about rationing to professionals behind closed doors' (Cochrane *et al.* 1991, p1039). There is also increasing pressure to have these decisions taken by different professionals. Making the process explicit has been accomplished by making the process more specialised, thereby introducing at



the same time a greater need for communication and mutual understanding of the issues. The separation of purchasers from providers of health care in 1991 placed purchasing authorities in the position of having to set priorities and make decisions about how to 'get the greatest improvements in health for the resources they invest' (Cochrane *et al.* 1991, p1039). According to Harris (1993, p159) 'when resources are tight the debates about priorities no longer focus on where services can be developed or improved but instead centre on what is to be dropped, restricted or otherwise rationed'. Many people today believe that rationing needs to become more explicit, but Maynard (1996) points out that there is no clear evidence and publicly accepted set of principles in place, to help guide purchasers as they determine how to spend health care resources.

Purchasing authorities, either consciously or implicitly, make decisions about which service to include and exclude from purchasing contracts. Chadwick (1993, p85) suggests that in setting priorities purchasers need to take account of the issue of justice because, she states, 'it is important to have a method of priority setting that is fair'. She describes three conceptions of justice that have relevance to the rationing debate. These include the ideas of 'just desert', need and utility. Rationing in terms of 'just desert' centres on the idea that 'a persons or groups lifestyle may be relevant to whether or not they deserve priority in health care ' (Chadwick, 1993, p87). Those who ascribe to this view commonly point to smokers or people wanting tattoos removed. Chadwick claims that this view does not give sufficient weight to social causes of disease nor to the context in which the choices are made, and therefore does not provide an adequate basis for resource allocation. However, there is evidence from recent research that a substantial minority of the general public believe that individuals who

contribute to their own illness (for example through smoking or drinking) should be given lower priority in health care (Bowling, 1996).

The second conception of justice relevant to the rationing debate holds that it is just to allocate resources according to need. In this view 'equal needs should be given equal consideration, whatever the individual merits of the person' (Chadwick, 1993). As Holliday (1992) notes, the NHS was founded on a strongly egalitarian principle in which 'access to health care was not to be determined by wealth, privilege or advantage, but by need'. The House of Commons Health Committee (1995) set up by the government to study the purchasing process in the NHS expressed this view and stated that the purchasing decision should be based, as far as possible, on firm assessment of need and should take full account of the epidemiological effectiveness and cost effectiveness data.

## **Health need**

There are different approaches for defining the criteria against which to assess health need. Wilkin *et al.* (1992) describe three such approaches. In the first approach, the World Health Organisation's (1980) definition of health as a state of complete physical, mental and social well-being represents the ideal standards against which health needs can be assessed. This approach has little practical value in defining health need. The approach upon which social and health policy tends to rely defines minimum standards against which need can be assessed (e.g. minimum standard of physical function in terms of walking, washing, or dressing). An approach that falls between the ideal and minimum standard approach defines health need in terms of comparisons with the standards achieved by other groups or individuals. Wilkin *et al.* (1992) state that in practical terms, the comparative approach offers a compromise between what they describe as 'largely undeniable ideals and highly restrictive minimum standards'.



The third view of justice relevant to the rationing debate starts with the idea of health need and holds that it is fair to prioritise between needs (Chadwick, 1993). In this view, the idea of utility or treatment effectiveness is important, since it is believed that resources should be allocated where they produce the most benefit. In a utilitarian view of justice, priorities should focus on what is expected to lead to the best possible outcome (Chadwick, 1993). A problem with using this view of justice in order to allocate health care resources relates to the fact that evidence about the effectiveness of many modern forms of medical treatment is non-existent. 'Some estimates have suggested that only about 15 - 20% of medical interventions have been evaluated and shown to be effective' (Coulter, 1994, p23). The lack of evidence regarding the effectiveness of many medical interventions represents a considerable problem for the NHS, and it underlines the need for more outcomes research. It also explains the current emphasis in the NHS on evidence-based medicine, which has the agenda of aiming to base the use of therapeutic interventions on scientific evidence rather than upon 'tradition and public expectation' (Doyal, 1995, p278).

## **Public consultation exercises**

Health authorities are now expected to consult the public on health matters and to incorporate the public views into purchasing decisions. The government directive Local Voices gave purchasers advice on different ways in which they could include the public voice in the purchasing process (NHS Executive, 1995). The rationale for this advice, writes Bowling (1992) is that 'while experts within medical and health care specialities and professions can advise on clinical *facts* in priority setting, only members of the community can express community health *values*' (Bowling, 1992).

There have now been several local and national surveys in the UK to explore the priorities of the general public (Richardson *et al.* 1992; Bowling, 1993; Heginbotham, 1993; Bowling, 1996). From a focus group study (Brown, 1995) it can be seen that while people believed that there was a need to prioritise services, they were aware of the tension between collective and individual claims on health services, and a strong resistance to the idea of prioritisation was also evident. High priority on these types of study is given to treatments for life threatening or painful conditions. The findings of these studies also give high priority to life saving treatments by the public, even though in abstract terms the public claims to value the saving of life with quality rather than simply extending life as long as possible (Bowling, 1993; Heginbotham, 1993). Perhaps this reflects the paradox that society generally values life (being alive) above the quality of life, although it is unclear from these studies if there were any relevant age or cohort differences in perception.

Public consultation exercises have only begun to explore the public's view about health care priorities. Some researchers believe that the public are not, at present well enough informed to engage in the prioritising process, since they lack the basic information about health services and costs and benefits of different treatments (Richardson *et al.* 1992). At the same time there is research to suggest that the public wants to be part of the process even if they lack certain information (Richardson *et al.* 1992; Brown, 1995; Bowling, 1996).



## **‘Giving people a say’: lay participation**

The section begins by describing lay participation in care as an umbrella term used for many different concepts within the literature. Next, it explores the various levels on which lay participation in care is a key concept in relation to two conflicting legacies and the emergence of lay participation in care as a key concept within a changing health service is explored. Lay participation means different things to different people and it is suggested that this plurality of meanings has led to confusion not only in the literature but also in health care policy and practice.

Within *health care* settings and practice, lay participation in care is fundamentally concerned with the involvement of non-professionals in the delivery of care in health-related institutions (e.g. hospitals) or the wider community. It is a loose term that is widely used in the literature generated by many different and wide ranging disciplines (medical sociology, health psychology, social policy, nursing and medicine). Overall, the body of knowledge is somewhat fragmented and inconclusive. Research in the name of lay participation in care covers a wide variety of activity, approaches and facets which include: focus of control, self efficacy, information giving, patient education, compliance, goal setting, informed consent, decision-making, consumer satisfaction and self empowerment.

Lay participation is currently part of the political rhetoric. However, on closer scrutiny, some activities labelled as lay participation in care, reveal little evidence of meaningful partnership between health professionals and the public. The limitations of some of its meanings and understandings in the literature are discussed in this chapter.

Lay participation in health care constitutes a radical change in practice. It emphasises an awareness and respect for the integrity of the individual and

advocates a person-centred, holistic approach to care which does not focus on 'patients as disease entities' but instead emphasises individuals' unique perceptions of health and well-being. Unlike traditional approaches to care based on rational technology and reliance on medical expertise, lay participation in care encourages people to be self reflective and questioning about their needs and health care provision. It is not a neutral, value-free process but more a questioning and supporting initiative, embracing a variety of approaches to health care. This constitutes a radical change in health care thinking and practice and requires health professionals to move away from their traditional roles of 'doing things for patients' and to develop educative, supportive and facilitative roles.

The meanings and interpretations of patients' desires for health care are central to lay participation which bases practices on democratic participation and is concerned with enabling patients or clients to identify those aspects of care important to them. Thus lay participation in care can be regarded as political, sharing many of the underlying concepts of Habermas's critical social science (Habermas, 1972). These concepts and values include: holism, partnership, public participation, collaboration, equity, co-operation, and enabling. From a review of the literature lay participation in care is generally viewed positively by both health professionals and lay people (Brooking, 1986). However, other research suggests that health professionals pay mere tokenism to the concept (Brownlea, 1987) and rather than offering empowerment, use lay participation in care as a means of manipulation towards compliance (Brearley, 1990).

Furthermore it is suggested that patients themselves appear to be reluctant collaborators (Waterworth and Luker, 1990) in health care practice.

## Lay participation and the individual

Lay participation can be regarded as the involvement of individuals in their own health, often referred to as *self-care*. Levin defines self care as:

a process whereby a lay person functions on his/her own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the healthcare system  
(Levin *et al.* 1989, p175)

From this perspective, lay participation in care is concerned with involving all people within a 'well being-illness' spectrum (Dines and Cribb, 1993). In self care there is as much focus on involving the *well and healthy individual* in health maintenance and disease prevention as there is concern with involving the unhealthy individual in disease detection and treatment (self diagnosis, self medication, self treatment). The extent of possible self care is clearly going to be determined by an individual's level of dependence or independence in relation to their position on a health illness continuum, plus their knowledge, attitudes and skills.

Lay participation in care is as much concerned with the activity of health-related decision making as with the development of practical skills in order to promote health, prevent disease, detect and treat illness or adjust to long-term chronic illness and death. Decision making can be seen at the individual level in terms of making decisions about the patient or client care or at the wider community or society level of making decisions about local and national policy issues that influence health.

## Lay participation and the professional

Nurses' perspectives on lay participation are reported by Jewell and colleagues (1994) who used an ethnographic approach to uncover the perceptions of primary nurses towards patient participation. Group discussions were led by the



researcher with four primary nurses within a rehabilitation unit for older people. Whilst the small size of the study militates against generalisations, it provides some understanding of nurses' perceptions of lay participation in care. Study participants recognised that lay participation in care concerns a general approach to care rather than a specific procedure. The nurses identified the need for both formal and informal mechanisms to facilitate lay participation in care. The formal mechanisms include the involvement of patients, through the nursing process, in planning and evaluating care whilst the informal mechanisms refer to the on going nurse exchange. The participants also identified that collaboration involves mutual informing or negotiation between patient and nurse. Whilst this study gives clear insight into nurses' perceptions of lay participation, it still only deals with their understanding at a theoretical level. Of greater interest would be whether, and how in reality, they either formally or informally involve patients in their care. Given that lay participation means different things to different people, one might reasonably expect researchers to be more explicit about their own values and principles guiding their understanding of the concept. Instead there is a tendency among 'researchers' in general to draw on general definitions and fail to discuss findings in relation to a broader understanding of the philosophical and political issues that underpin the concept.

Much of the original theoretical basis for primary nursing ensued empowerment and patient participation in their care. However, health professionals in rehabilitation settings are set in a task-oriented approach rather than a professional development model of care. A proposed system of care which focuses on 'patients as individuals' is difficult to adopt and is incompatible with the 'task-oriented practice' that prevails. So while in nursing, for example, there has been a strong move away from 'task' oriented to 'person' oriented approaches how this is actually achieved remains an empirical question.

## Public participation

Making decisions at the level of community or society is often referred to as *public participation*. Maxwell and Weaver (1984) offer five perspectives on what is meant by public participation which can be seen in ascending order of public demands: consumer protection; public consultation; openness of management decision making; full management participation by public representatives; and heightened individual responsibility and power.

Consumer protection represents the lower or minimum end of the spectrum of public demand. It refers to the degree of protection against exploitation expected of any user of a service. It includes professional standards, licensing of medicines and practitioners and providers, ethical committees governing research and the notion of informed consent.

Public consultation is concerned with taking into account the feelings and opinions of lay people about services under offer. This does not necessarily imply lay dissatisfaction when views are not acted upon. In some instances it is enough for the provider to be seen to be listening through regular consumer surveys and for mechanisms to be provided for suggestions and more formal complaints. On the other hand there are some issues lay people feel more strongly about and would wish their views to radically change services. The establishment of voluntary organisations to actively campaign for changes in policy and practice exemplifies this. This form of participation is frequently described as consumerism but needs to acknowledge both the views of consumers of health care (patients, clients, self care groups) and the views of citizens in general (Day and Klein, 1984).

Openness in managerial decision-making is also seen as part of public participation. Maxwell and Weaver (1984) suggest that since the health service

deals with sensitive issues and is such a large user of public money, the lay public have a right to know how decisions are arrived at. The establishment of user groups within health-care practices allows more opportunity for sharing the process of decision-making.

Full management participation by public representatives allows communities to share in the processes of health policy and service provision. For example, Community Health Councils (CHC) were established to represent the interests of the lay public in the health service.

Finally, heightened individual and community responsibility and power are seen as the last form of public participation which engages the most public accountability and participation of all the five public perspectives (Maxwell and Weaver, 1984). This particular perspective is based on the notion that health has become over medicalised (Illich, 1976; Kennedy, 1981) and that the balance must be redressed through empowerment of individuals and communities taking more responsibility for their own welfare.

## **Historical legacies**

Whilst lay participation in care can be seen to function at different levels, the nature of lay participation in care very much depends upon its underlying philosophical underpinnings. Van den Heuvel (1980) suggests that there are two conflicting historical legacies that have profoundly influenced the conceptual understandings of lay participation in care: one emerging from a *humanistic perspective* emphasising self determination, and the other described as the *bureaucratic approach* to consumerism based on controlling costs, outcome and efficiency. These two distinct historical legacies have led to a plurality of perspectives and confusion of meanings in the literature on account of their different and often conflicting political perspectives.



## The humanistic perspective

Humanism stresses the importance of people and their capabilities. It is thought to have emerged as a challenge to the medical dogmatism in the mid 20<sup>th</sup> century (Steele *et al.* 1987).

According to Steele (1987) lay participation in health care in the form of the active participation concept has risen and fallen for the past two centuries. Prior to the 18<sup>th</sup> century most individuals had responsibility for their own health care, usually as a result of necessity (only the wealthy or educated made use of professional services). Within the community people helped each other and some individuals were recognised as having special skills but there was little participation by the majority of people in the development of health care policy. However, the last part of the 20<sup>th</sup> century saw an increase in medical technology in terms of effective disease prevention (immunisation) and curative measures (antibiotics). Together these fostered a gradual increase in medical authority and the 'retreat of private judgement' (Starr, 1982). Medicine became established and respectfully recognised as a scientific discipline as doctors enjoyed unparalleled dominance and their medical authority was seldom questioned and patient acquiescence was assumed (Steele *et al.* 1987). Engels (1977) suggests that medicine as an institution became a formidable power of social, political, and economical invested interests and as a result demands for a return to lay participation in care have been slow to take hold.

The challenge to medical ideology arose in the mid 20<sup>th</sup> century as a result of several influences:

1. Influence of existentialist philosophy with its emphasis on self determination and its encouragement of mistrust of authority and doubts about technology (Thomas, 1983).

2. The impact of health statistics revealing the chronic and preventable nature of most illness (Jacobson and Smith, 1991).
3. The effect of advances in medical technology resulting in patients being discharged from hospital earlier or being cared for at home, or in the community.
4. Development of consumerism in society, arising from a better educated public with more access to health-related information through the mass media and leading to public demands to be kept informed and more involved in their care (Jones *et al.* 1987).

These influences challenge the medical domination of health care. This requires health professionals to rethink their roles in relation to lay people and to develop 'educative and supportive roles' rather than continuing to act in the traditional role of 'expert doer'. This challenge to medicine particularly as an occupational elite (Harrison *et al.* 1990) is further supported by the recognition that the vast majority of care in the community is being given by informal carers (Parker, 1985) and also by the public realisation that lay organisations (voluntary and self help groups) as well as alternative and complementary practitioners make useful contributions to health practice. This, together with the growth of consumerism, has done much to challenge the traditional notions of the doctor-patient relationship particularly in areas of patient access to information about their health care and the determinants of the quality of care.

Kickbush (1989) suggests that past researchers tended to concentrate on matters related to the organised professional health care system such as the organisation of treatment which focused on the corresponding patient-professional interactions. Physician authority was rarely questioned and patient behaviour was summed up as 'compliance'.

Medical sociology as a discipline has questioned and criticised the system. The humanistic or democratic perspective embraces the notions of empowerment, civil rights and equality of opportunity and is citizen-led (Beresford and Croft, 1993). Empowerment is a critical concept for practice and four important dimensions can be identified: empowering people to challenge oppression and discrimination and take greater charge of their lives; offering people control over personal dealing with agencies; enabling people to take power by helping them gain confidence, self esteem, assertiveness, expectations, knowledge and skills, and offering opportunities, structures and resources which are open to people's involvement. Some environments, however, are disempowering (Beresford and Croft, 1993). There are therefore wider issues for organisations and services to facilitate lay participation in care through empowerment. These are: agreeing not imposing participation, using an amalgamation of top-down and bottom-up approaches, developing skills in individuals and political change, bringing together service providers and users, changing outcomes as well as attitudes, equipping people to set their own standards for quality control and evaluation, having a flexible approach to increasing people's say, recognise and tackle different tensions and chains of accountability in different service providers, creating a positive climate for experimentation and risk, and finally disseminating good practice (Beresford and Croft, 1993). It is worth noting here that a full understanding of these concepts seems lacking from the development of many approaches to outcome measurement (see chapter 5).

From this discussion it can be seen that the emergence of lay participation in care is the result of a humanistic perspective emphasising self determination. However, another conflicting historical legacy has similarly given rise to this concept based on controlling costs, outcome and efficiency. Van den Heuvel has described this as the bureaucratic approach to consumerism (Van Den Heuvel,



1980). This alternative perspective to the development of lay participation in care is explored in the following section through an examination of the changing health service. Finally, it is argued that these two perspectives have profoundly influenced the conceptual interpretation of lay participation in care and have led to a confusion in meaning in health care literature, policy and practice.

## **The bureaucratic perspective**

This section argues that the growth of managerialism which has occurred in response to financial and organisational threats to public services has led to a different understanding of lay participation to that of the humanistic perspective. The humanistic perspective based on the individual, empowerment with its emphasis on participation, partnership and power-sharing is in direct conflict with the bureaucratic perspective based on consumerism, with its own emphasis on economy, effectiveness and efficiency.

Health care provision has evolved over time in response to changing demands. The NHS was seen as a great step towards the goal of an equitable distribution of health services by making services free of charge at the point of use (Baly, 1973). However, since its beginnings two major issues have threatened the realisation of this goal: finance and the organisation of services (Leathard, 1990). One of the outcomes of these threats has been for lay participation in care to have been given more emphasis in health policy documents. However, this emphasis reveals a lack of understanding of the concept of lay participation in care.

The first issue in the historical legacy of the bureaucratic perspectives concerns finance. From its beginnings, the NHS has tended to generate costs and place increased demands on public expenditure. The ideology behind its creation was that there should be no financial constraint on patients receiving treatment

according to need (Klein, 1983). It was assumed that there was a fixed quantity of illness in society and the NHS would reduce this in time (Beveridge Report, 1942). However, advances in medical technology and improvements in public health mean that people are living longer (chapter 2) and with a range of chronic illnesses (chapter 4) and this, together with increases in consumer expectations, has placed a never ending 'burden' on the limited resources available for health care. Over the decades more money has been poured into the health services but this public expenditure has never met the changing demands for health care.

Various initiatives have been set up to review finances and plan priorities (initially Department of Health and Social Security (1976a; 1976b). The main thrust of these was to suggest more efficient uses of resources and place greater emphasis on community care and preventative services. As a result of economic stringency, lay participation in care, under the guise of consumerism has become increasingly important within policy documents (Department of Health, 1989; Department of Health, 1990; Department of Health, 1992).

The second issue that threatened the NHS was the organisation of services. In turn this has led towards the adoption of the notion of lay participation in care. According to Leathard (1990) four on-going issues surrounded the effective organisation of hospital provision up until the late seventies: resource priorities, controversy over pay/beds, staff shortages and above all the reorganisation of the whole structure of the health service. Reorganisation of the structure in 1974 was needed due to an inherited problem of fragmented and uncoordinated services. Unfortunately, it attempted to reconcile conflicting policies (managerialism and professionalism) and this in turn led to further crisis and chaos (Leathard, 1990).

During the late seventies and early eighties, the depressed economy imposed cuts and efficiency savings on the NHS. During this time the government sought alternative methods of health care provision including the private sector, voluntary sectors and informal caring by the family (Department of Health and Social Security, 1981). Whilst the government was keen to endorse the contribution made by people to health care, it ignored the emerging research evidence indicating that informal care had its own costs to bear on those individuals who became carers (Department of Health and Social Security, 1981). The endorsement of lay participation in care would appear to have been driven and solely led by financial interests.

In seeking to prepare health professionals for a role in preventing ill health in the community the government supported the idea for nurses, midwives, health visitors and health educators to develop their role as health promoters (Department of Health and Social Security, 1976b; Department of Health and Social Security, 1977; Department of Health and Social Security, 1981).

However, their emphasis was very much on health promotion at the *individual* level, such as changing lifestyles, rather than addressing more fundamental issues within society concerned with inequalities in health or social injustice.

Thus the government supported the development of the health professionals role in health promotion for cost-effective reasons. There is a debate as to whether promoting health at the individual level is actually effective, if you fail to take account of circumstances and involuntary lifestyles (Blaxter, 1990).

The 1980s saw a period of rapid upheaval and unparalleled change in the health services. It began with a search for better management which did nothing to re-address the issues being raised by a conflict of understanding of the meaning of health. The introduction of general management in the NHS based on the Griffith's model (The Griffith's Report, 1983) had allowed little time for public or



professional consultation on its recommendations. If lay people were to be involved in care, it is argued, they should have been given more opportunity to influence how the service was to develop. The paradox here is that the new management proposals espoused a consumerist spirit but the structures actively inhibited meaningful lay involvement.

Throughout the 1980s a new wave of managerialism brought new concepts and ideas concerned with resource priorities, targets and crucially, outcomes. The new managerial approach has two themes: decentralisation and markets used to match provision to consumer demand. The chief criticisms of the approach concern the emphasis on financial efficiency, the limitations imposed on choice, the channelling of innovation towards increased economy, the practice of selectivity and the problems of constructing collective outcomes through the aggregation of individual choices (Taylor-Gooby and Dale, 1981). For example, the Citizens Charter (Department of Health, 1991) promotes a range of methods for improving basic standards, the availability of choice, the quality of provision and value for money in the public sector, including competition, contracting out, privatisation. The Charter also emphasises the monitoring of services. However, Taylor-Gooby and Dale (1981) argue that the measures chosen to monitor services are highly controversial and there is considerable concern that the desire to meet standards skews resource allocation and stifles innovation within services. Whilst such approaches emphasise lay participation in care through choice, critics argue that choice is constrained by knowledge and availability of alternatives, which in turn may be controlled by overall budget and policy objectives. In this sense choice is meaningless and merely serves as rhetoric.

By the late 1980s the government was advocating increasingly the role of lay people in health care but the limitations of what was available immediately became apparent. The 1989 White Paper 'Working for Patients' (Department of

Social Security, 1989) had a central theme of consumer issues (standards, quality assurance, communications, choice). However, it really did little to enhance consumer power. Whilst lip service was being paid towards reorienting the health service towards the more health promotion line with the WHO statement of 'health for all' by the year 2000 (World Health Organisation, 1980), little was being done to encourage public participation in health:

Central government policy in relation to health has recently concentrated on the pursuit of greater marginal efficiency within the NHS and the encouragement of public sector alternatives. To plead for more effective public participation is not necessarily to conflict with either of those two approaches, but is less fashionable than it might have been a decade ago ... no combination of services is going to be satisfactory for so long which does not explicitly recognise the importance of participation by the individual, the local community and national organisations in health matters

(Maxwell and Weaver, 1984, pp118-119)

Lay participation in care became popularised within management through consumerism, but the extent to which true partnership was being offered is doubtful. The term itself was fraught with ambiguity. Stacey (1976) suggests that the concept of the patient as a consumer undervalues the patient's status and is a sociological misconception since in reality patients are both consumers and producers of health by virtue of their participation in the health care process. There is also an important point made by Hart (Hart and Halperin, 1994) which emphasises that health professionals are the consumers on behalf of patients in any health-care market. Van den Heuvel (1980) suggests that the meaning of the concept is in need of clarification and that research on consumer satisfaction and evaluation are limited since there is presently no real means of involving consumers in health-policy and argues that consumer participation should also allow for consumers to assess health needs as well as to comment about the organisation and availability of services.

More recent reports on the health service all advocate the notion of the patient as a consumer (Department of Health, 1992). Freedom and consumer control were key features of the Conservative Government's social policy on the basis that state dominated services deny people the opportunity to engage in real choices (Clode *et al.* 1987). Individual choice and individual purchasing power are likely to mean that those with greater levels of resources can purchase a better quality of service. However a tension exists between equality and liberty. Clode *et al.* (1987) identify three levels of consumerism and argue that whilst in 'fiscal-led' consumerism the distinction between equality and liberty is clear, in 'organisation-led' consumerism the distinction is less obvious and in 'individual led' consumerism the right to freedom needs to be balanced more keenly with the right to treatment.

Recent writers on health policy have suggested that the government is using the new managerial approaches (efficiency savings, performance indicators) to delay or avoid crisis in the welfare state (Harrison *et al.* 1990). They suggest that health policy can be best explained by a combination of neo-elite and neo-Marxist theories. Neo-elite theories are concerned with occupational elites and may explain why the medical profession has come to dominate health care practice. Neo-Marxist theories relate elites to the class structure of the capitalist state. They argue that the demand for welfare state expenditure rises over time with demographic changes and expectations but that capitalists resist increasing taxation to accommodate this by placing instead an emphasis on cost efficiency. Harrison *et al.* (1990) argue that this is for short term gains only and foresee either a gradual dismantling of the welfare state or for capitalists to support the growth of the NHS. Thus lay participation in care can be seen as a political ploy by past, if not present government, to 'paper over the cracks' of a disintegrating welfare state.



There are also clear examples of the ways in which recent government policy actually inhibits true participation and partnership between lay people and professionals. For example, it is interesting to note that the major changes in the NHS contained in the NHS and Community Care Act (1990) and in the introduction of the Citizen's and Patient's charters (1991) were seen to strengthen the voice of the patient within the NHS, but have also led to the marginalisation of the Community Health Councils (CHC's) which were established to provide a formal and statutory mechanism for the consumer voice.

This bureaucratic consumerism perspective is therefore very different to the humanist perspective of lay participation in care and is clearly informed by different political and traditions of the importance of welfare.

## **Summary**

From the above it can be argued that not only is lay participation in care practised on different levels, but also its nature and development are derived from two historical legacies of conflicting political intent. Lay participation is seen to mean different things to different people, depending on their individual principles and values. One has to question whether government policies which advocate lay participation in care, actually offer, in practice, freedom of choice to the individual. Perceived scarce resources might suggest that the government is more concerned with off-loading its responsibilities onto the consumer than being concerned with freedom of choice and improving the quality of health services. Rationing on the basis of age underpins ageism (Editorial, 1993; Mulder *et al.* 1998; Jennett, 1995). By paying lip service to lay participation in care the government might wish to make its policies more acceptable to the public. True participation in care would require radical changes in health services to become more than social rhetoric (Brearley, 1990). It would require a different type of

professional capable of sharing knowledge with lay people rather than limiting access to specialist knowledge to experts only. It would also require freedom of choice as to whether one participated or not. As Cook (1987) pointed out: 'unbridled consumerism is not even always what the consumers want'.

Clearly health professionals have drawn on ideas from both historical legacies to understand lay participation in care. Most health professionals are perhaps more likely to value humanism, but in a rapidly changing health service, which emphasises cost effectiveness, the pressure to work in a less humanistic manner is ever increasing. This has important implications for 'person-centred' care and 'person-centred' outcome measures both in theory and in practice.

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## **Chapter 4**

### **Living with chronic illness and disability in later life**

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Disablement lies in the construction of society, not in the physical condition in the individual. However, this argument is usually rejected precisely because to accept it involves recognising the extent to which we (disabled people) are not merely unfortunate, but are directly oppressed by a hostile social environment

(Drake, 1996)

It can be seen from the previous chapters that older people face specific problems as a result of prejudice because they are old. The onset of illness means that they develop further problems; those specific to all chronic illnesses and problems which may be specific to their specific condition, for example, stroke. In this chapter the impact of living with chronic illness and living with disability are considered.

#### **Living with chronic illness**

It has been argued that any examination of the impact of chronic illness and its treatment should focus on physical, psychological and social functioning (Spitzer, 1987). The impact of chronic illness may be physical, in as much as it may limit what we are capable of; psychological, in as much as it may oblige us to face new definitions of who we are; and social, in as much as it may affect our relationships and interactions with others.

The growing number of people living with chronic illness (Bury, 1982) and the dramatic increase in their survival (Corbin and Strauss, 1987) represents a major challenge to both society and to health care professionals, who must assist



people to achieve and maintain the optimum quality of life (see chapter 5). The social and psychological impact of chronic illness upon coping mechanisms and lifestyles of individuals, and their family and friends, is momentous and has been widely investigated (Bury, 1982; Corbin and Strauss, 1987). Current literature focuses on notions of 'self-help', 'empowerment' and 'uncertainty'. An increasing number of individuals, through the provision of appropriate information, are empowered to self manage their conditions effectively. Consequently, they are able to cope more successfully with a wide range of chronic illnesses. This chapter first explores and discusses some aspects of coping with chronic illness from selected theoretical perspectives. The empirical evidence on information needs in chronic illness, the impact of information provision on coping and the impact of living with disability resulting from chronic illness are considered.

Themes which are pertinent to disabled people in society are also explained as they are useful in understanding many of the problems which many *older* people with disabilities face. This includes definitions of disability; the different theories about disability; the ideological constructions of disability; cultural and social considerations of disability; the structuring of disabled identities and the social construction of the disability 'problem'. The discussion focuses on how these issues effect impact on all people, regardless of chronological age, but it is significant that 'older people' form the largest proportion of this group, as there is increased risk of chronic illness and disability with ageing (Bond *et al.* 1993).

Finally the combined effect of living with disability and chronic illness and being older in society combine to form a situation of triple jeopardy for older people.

The key challenge here is to bring together the traditions which have explored chronic illness and those which have provided an analysis of disability. One of the problems has been that they have not been integrated within the literature.

The disability literature is generally concerned with disablement, perhaps the

social status following chronic illness, but also other adverse life events, such as accidents. It also tends to be about younger people, although sometimes, where it suits the writer, older people are incorporated into the discussion. The chronic illness literature is about *process*, and therefore places only a limited emphasis on structure. An integration of the two concepts is not evident in the literature, yet this is essential to contribute to the debate.

## **Dominant themes in the literature on chronic illness**

Chronic illness affects patients of all ages and currently 31% of males and 32% of females in England and Wales are affected (OPCS, 1993). It is more prevalent among the poorer members of society (Townsend *et al.* 1992) who may be less articulate about their health concerns (Cartright and O'Brien, 1978) and exerts major physical, social and psychological effects on individuals and their families, who in addition to fulfilling their usual social roles and obligations, are expected to meet the needs arising from illness. The onset of chronic illness, represents an assault on the person's physical self, self worth and sense of identity (Keller and Nicolls, 1991). Most chronic conditions are, by definition, intractable to treatment (Radley, 1994). A distinctive characteristic of chronic illness is its temporal dimension (Toombs *et al.* 1995). Unlike acute illness, chronically ill patients do not continuously adopt the 'sick role' (Wilmott, 1989), but incorporate the illness and its implications into everyday life (Johnston and Marteau, 1990). However, interventions in chronic illness are still being dominated by approaches that are more appropriate to acute conditions (Nolan and Nolan, 1995). Coping requires people to manage the diagnosis (Bury, 1991; Braden, 1990), crisis of illness and subsequent adjustment. Kirk (1992) observes that the resulting loss of physical and social confidence impacts upon coping (Rosenberg, 1991; Felton and Revenson, 1984).

Conrad (1990) identified a number of broad themes around which sociological research into chronic illness experience has focused, including, the problem of uncertainty; the impact on a person's life biography and the need for reconstitution of self; the problem of managing the condition and the impact of the condition on the family.

## **The concept of uncertainty**

Uncertainty is a cognitive state created when an event cannot be adequately defined or categorised due to a lack of information. It is a major factor influencing expectations about chronic illness, treatment and prognosis (Hilton, 1992). A number of studies have shown that people with signs and symptoms of this try to ignore or normalise their situation (Cowie, 1976; Bury, 1982; Cohen, 1997) then as symptoms persist, try to find explanations for them (Canam, 1993). Robinson (1988) described this as 'diligent detective work' which involved reading, discussing symptoms with friends and relatives and interpreting overheard conversations between medical staff. Because of the vagueness of early symptoms (Ray and Ritchie, 1993) or the problem of medical scepticism (Burton, 1975; Cohen, 1997) arriving at a diagnosis may take a long time. This prolonged, diagnostic uncertainty may mean that although the affected person sees himself as sick, the condition cannot be legitimised medically. Therefore, when ambiguity is eventually resolved by receiving a diagnosis, this may be welcomed rather than rejected even when it is unfavourable (Bury, 1982). The biographical disruption encountered by patients when the diagnosis brings to an end one set of uncertainties but at the same time creates another (Cohen, 1997) requires the patient to confront questions about the nature of his or her life from now on. Radley (1996) observes that uncertainty in chronic illness is endemic at all stages of the condition and not just limited to one period of time or situation.



## **Reconstitution of concepts of self and life biography**

Williams (1984) suggests that the sense of meaning and order which individuals normally experience as a result of being constantly engaged in the interpretation of daily life events is thrown into disarray by the onset of chronic illness. This is only restored coherently by the individual reconstructing their 'biographical story or narrative'. Misfortunes such as chronic illness are seen to originate from particular past incidents, so interpretation of the past gives meaning to the present (Scambler and Hopkins, 1990).

### ***Loss of self, functional limitation and social isolation***

Charmaz suggests that people with a chronic illness may suffer disruption to their daily lives which is beyond any physical discomfort and that restrictions may be externally or self-imposed. Charmaz (1983) comments that chronically ill people can experience a 'crumbling away of former self images without simultaneous development of equally valued new ones', which she claims is a fundamental form of suffering for them. She attributes this loss of sense of self, to living a restricted life because of the functional limitations imposed by the condition and existing in social isolation possibly because they lack the energy or time to sustain social activities while coping with their situation. Earlier friendships may wane because the ill person no longer shares the same social world increasing the sense of social isolation. This may be linked to an experience of discredited definitions of 'self' and the feeling of 'becoming a burden' to others. This feeling is rooted in physical dependency; the inability to fulfil former obligations and pursue former activities and interests while contending with the functional limitations and treatment regimes which accompany their condition. The resultant feelings of uselessness to self and others compound a sense of social isolation.

When chronic illness strikes, the failure of the body may lead to failed 'performances' with functional limitations. Accommodation of this, in the form of modified or omitted 'performances', must occur. Since the degree of chronic illness can vary over time, so can the degree of body failure, and these have to be continuously negotiated. A person's perception of their ability to carry out 'performances' is closely linked to their sense of self (Corbin and Strauss, 1987) and the onset of chronic illness threatens this and forces new biographical projections. This means that the person you were and the lost past must be set aside and new biographical projections must be made, to correspond with the projections about the course of the illness - what Corbin and Strauss (1987) describe as the *illness trajectory*. Whereas, prior to the onset of illness, the projected biography appeared certain, it now becomes unclear, because of the uncertainties about the course of the condition. Corbin and Strauss (1987), in an analysis of the accompaniments of chronic illness, propose three types of work which people with chronic illness do: illness trajectory; everyday work; and biographical work. The first of these involves not only medical aspects of the illness management, such as maintaining treatment regimes, preventing crisis and managing symptoms, but also non-medical aspects associated with its impact, such as accommodating it into the lives of the person and their families. Everyday work encompasses the daily round of tasks such as house-keeping, occupational work, marital work and thus involves interactions with spouse, family and friends. Finally, biographical work is concerned with redefining and re-integrating the identity and refocusing direction, including the establishment of new priorities of what is important in life. Crucially, in a society which emphasises 'doing', not 'being', those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life



(Charmaz, 1983, pp190-191). Their illness becomes a major source of their social identity.

Some individuals feel stigmatised by chronic illness and appear to experience a loss of self and suffer low self esteem. Crocker and Major (1989) while acknowledging there is no doubt that prejudice and discrimination have substantial negative consequences for members of stigmatised groups, suggest that some individuals may protect their self concept by selectively devaluing those dimensions on which they and their group fare poorly and valuing those where they excel, and by comparing outcomes with other members of their stigmatised groups rather than with those of the generalised 'other'.

Modern treatments are of course limited in what they can achieve in terms of altering the fundamental course of the disease and may lead to a new set of problems or side effects (Bury, 1991, p458). Patients with a chronic condition often become experts in their own treatment, weighing up associated costs and benefits and adhering to or adapting their prescribed treatment regimes accordingly.

## **Impact on family relationships**

One of the features of chronic illness noted by Charmaz (1983) is the toll it takes upon others involved and the changes of relationships. Providing continuing assistance and support has costs for carers. Anderson (1988) examined the quality of life of stroke patients and their carers, almost all of whom were members of their immediate family, and reported that tiredness, anxiety and depression were all common problems for the carers, as were restrictions in their social activities and feelings of isolation. The 'loss of self' experienced by many sufferers of chronic illness is also reflected in the sentiments of their carers. Communication problems, accentuation of pre-existing relationship problems,



increased social isolation and disorganisation of family routines have all been cited as factors which are influenced by chronic conditions (Venters, 1981). Significantly, Venters suggests that the way in which a family accepts or fails to accept a diagnosis of illness in one of its members may affect the progress of the illness.

Parker (1993) has commented that though there is a considerable body of research on the impact of care-giving in chronic illness, little specific attention has been paid to the impact of caring for a spouse who is chronically ill or disabled. Some married couples see their relationship strengthened by the experience, others perceived the effect as negative.

### **Coping with and managing chronic illness**

Coping is defined as the cognitive process which enables an individual to tolerate the effects of illness (Bury, 1991) and is an important buffer, maintaining coherence and personal worth in the face of disruption. Several authors (Braden, 1990; Radley, 1994; Ogden, 1996) observed that people display either an adaptive or maladaptive response to their illness. This dichotomy has prompted much debate and generated a voluminous psychological literature.

The literature on coping with chronic illness is grounded in the concept of reducing anxiety in vulnerable adults who are potentially exposed to a stress stimuli. The earlier 'dispositional' approach has been superseded by research which investigates different coping behaviours. Lazarus and Folkman (1984) propose that evaluation of illness as a stress consists of a primary appraisal of the relevance and seriousness of the event and a secondary appraisal of coping resources. Thus they claim that the *meaning* of illness to the individual is more important than its nature.

'Meaning' in chronic illness has been variously described and Bury (1991) distinguishes two types: one relating to the consequences for individuals everyday activities and the development of strategies for minimising the effect of disruptive symptoms on everyday life, and 'significance' which proposes that different conditions have symbolic, societal significance which will affect adaptation. Whilst illnesses may be stereotyped and stigmatising, for example, 'arthritis' or 'diabetics' (Jacoby, 1993), the illness meaning for the individual with chronic illness often changes at different life stages (Marteau and Johnston, 1986; Arpin *et al.* 1990). Bury (1991) comments that these stereotypes 'may have a profound influence on how individuals regard themselves and how they think others see them'.

## Information and knowledge

The conceptualisation of coping is founded on the relationship between health beliefs and illness beliefs. Lau *et al.* (1989) suggest that most people display positive health beliefs and that these underpin their illness beliefs.

Leventhal *et al.* (1980) and Lau *et al.* (1989) propose a theory of 'illness cognitions' which provides schema for understanding and coping with illness. Current research in this area suggests that patients employ either behavioural or cognitive mechanisms for coping (Lazarus and Folkman, 1984; Weinman *et al.* 1996). These are found to require an emotion based or problem based strategy (Lazarus, 1985), although in complex, stressful situations, some people use both together (Viney and Westbrook, 1982). Lazarus (1961) was one of the earliest authors to identify the link between chronic illness and psychological distress, and regards anxiety as the key psychological state that stands between stress stimuli and emotional and coping reactions. He introduces the concept of 'mastery' in relation to the patient coming to terms with the 'helplessness of the

situation'. In most life situations, individuals usually avoid circumstances which are threatening. However, illness and the accompanying stresses, can not be avoided but must be accommodated into the patient's life (Felton and Revenson, 1984; Cohen, 1993; Mishel, 1983).

Lazarus (1961) uses the analogy of the learner driver needing appropriate knowledge and skills to achieve complete command and mastery of the vehicle. In the early stages of learning, command of the vehicle is usually shaky and anxiety high. With increased knowledge and consequently the belief that he/she is in command, previously frightening situations can be met with security. Applying this analogy to illness, he suggests that the more knowledge and control patients believe they have the less vulnerable and uncertain they will be. This approach has been reinforced by other authors (Blalock *et al.* 1995; Martin, 1995; Mast, 1995; Nolan and Nolan, 1995). Personal resources such as skills, knowledge, experience, history of success in previous crises and positive health beliefs all contribute to a sense of security and anxiety reduction.

The evidence suggests, therefore, that patients' illness cognitions influence how they make sense of their condition (Leventhal *et al.* 1980; Johnston and Marteau, 1990; Marteau, 1989) and aid understanding at the different phases of their illness trajectory (Corbin and Strauss, 1991). Thus, illness cognitions are a prerequisite to coping strategies. Cohen (1993) and Mast (1995), emphasise the importance of information, assistance and support from health care professionals to minimise stress and uncertainty.

The significant progress in recent years in the study of uncertainty as a source of psychological stress (Mast, 1995) is matched by developments in the understanding of chronic illness. Carver *et al.* (1989) and Folkman (1986) suggest that the distinction between problem-focused and emotion-focused



coping is too simplistic, as is the theory that patients adopt intrinsically adaptive or maladaptive responses. Evidence suggests that the response to chronic illness is dependent on a number of factors, including situational characteristics and resources available to the individual (Carver *et al.* 1989; Folkman *et al.* 1986). There is now increasing conceptual convergence among researchers towards this approach.

As well as illness cognitions, adjustment to illness is a significant element of the coping process. Two components of this concept are the extent to which patients retain their normal roles in society and the way in which they incorporate the disease into their way of life (Radley, 1994). Leventhal *et al.*'s (1980) proposal of the 'self-regulatory model of illness behaviour' maintains that patients cope with illness in the same way as with other problems. Satisfactory information provision is perceived to be a contributory factor in their empowerment (Sharp *et al.* 1992; Griffiths, 1981) whilst frustration and increased stress result from unsatisfactory information provision. Of course, this position is complicated if expectations of information provision are low.

Bury (1988) emphasises that patient education material ought to be up to date, accurate and contain what the patients need and want to know (Arthur, 1995), although methods by which to establish this, given the diversity of needs, are unclear. Donovan and Blake (1992) and Kay and Punchack (1988) observe that patients want to know more about their disease, reasons for and results of investigations, treatments and prognosis. Kay and Punchak (1988) reinforced the ideal of information seeking behaviour described by Lazarus and Folkman (1984). Street (1991) reports that 54% of patients questioned had no information about their illness and 82% acquired most disease related information from television. Meanwhile, Caughey (1989) argues that the public are hungry for knowledge about their chronic health problems.

## Relationship with health professionals

There is a substantive literature on professional-patient communication and interaction, particularly doctor-patient interaction. Several studies question whether doctors and other health professionals fulfil their responsibilities and communicate effectively with their patients (Manfredi *et al.* 1993; Hagenhoff *et al.* 1994; Caughey, 1989) and suggest that health professionals and patients should meet to address the information needs of patients. Tuckett and Williams (1984) noted doctors' beliefs that patients forget much of what they are told and that they need to idealise their doctors 'whose very presence is the most powerful drug'. Maycock (1991) and Dixon and Park (1990) suggest that nurses are particularly in a position to ensure that information is acceptable to patients and with patients and other health professionals they ought to be collaborators in information development and provision.

Positive behaviour changes, increased knowledge and reduced anxiety have been reported in patients who received written and verbal information (Cook and Noteloviz, 1991; Vignos *et al.* 1976). However, far more significant increases in knowledge are noted for those patients who received verbal reinforcement of written information (Masur, 1981) which supports the problem focused approach.

'Information seeking behaviour', then, is a common coping strategy adopted by people with a chronic illness. Most health professionals recognise the need for patient information. Nevertheless, the process of patient education remains relatively haphazard (Myers *et al.* 1994). Because of the uncertain course of chronic illness, some doctors rely on patients to request information about the disease and its possible consequences (Nolan *et al.* 1986). This can result in confusion between doctors and other health professionals, individuals and their families about 'who knows what' and whose role it is to inform the patient (Jedlicka-Kohler *et al.* 1996). Patient information needs vary widely and are

influenced by a range of factors including people's previous knowledge, experience, level of cognitive ability and educational status.

The doctor-patient transfer of information is vital in the utilisation of illness cognitions and the development of coping strategies. However, this area of communication has not been subjected to a great deal of systematic and objective investigation. Ley (1989) has made the major contribution to the empirical evidence in the area of doctor-patient communication and he asserts that doctors 'find it hard to take communication seriously'. He proposes that doctors believe they already communicate effectively with their patients and that as busy people, they believe that communication is secondary to diagnosis and treatment. Obviously, it is difficult to generalise, but research on doctor-patient communication emphasises the process of information giving whilst neglecting to measure its effectiveness. Tuckett and Williams (1984) regard this as evidence that information giving in medical settings functions principally not to 'inform' but to 'control'.

Paradoxically, there is a widely held belief amongst doctors that their delivery of information to the chronically ill creates a 'fully informed' and 'compliant' individual (Levy, 1985; Ong *et al.* 1995). Patients displaying a poor understanding of their condition (Street, 1991) or not conforming to prescribed treatments are labelled as deviant or non-compliant (Ley, 1982). Unfortunately, very little qualitative evidence exists on patients' views about the information they receive, and its impact on coping. Consequently, it is difficult to discern whether poor compliance reflects patients' attitudes, or whether it is more a reflection of the standard of information, the mode of delivery or a lack of understanding of how the patient interprets the information to make sense of their own situation.



The earlier discussion of illness cognitions identified a major role for information provision in the empowerment of patients, leading to minimisation of uncertainty and greater adjustment to illness. Nevertheless, although most doctors advocate the notion of 'fully informing patient', the literature gives little credence to information provision in health care, except at a basic level.

In treating patients with cancer Ong *et al.* (Ong, 1995) suggest that doctors need to learn to handle their own anxieties about the disease in a way that does not hinder doctor-patient communication. One study reveals that the more questioning and anxious patients, received more information than those who asked less and displayed less anxiety (Street, 1991). Older patients (chapter 2) may be reluctant to question, and this may mask anxiety. Health professionals may also hold ageist beliefs about older people which may present difficulties in information sharing. If the difficulties inherent in compliance and satisfaction are to be successfully addressed it is vital that doctors' own values and beliefs on these topics are fully explored to help inform their communication with patients. There is an emerging psychological, sociological and nursing literature which addresses these issues. Hagenhoff *et al.* (1994) describe a study by nurses which investigated information needs of patients with heart failure and conclude that they need considerable education to enable them to provide effective self-care. They also highlight the initial period of hospitalisation as a window of opportunity for patient education about medication, risk factors and levels of activities, although whether this is an appropriate time or setting to do this is not proven. Nevertheless, although nurses used these opportunities to provide information, they acknowledge that this strategy was not informed by empirical evidence of patients' perceived learning needs and was a nursing rather than a multi-disciplinary initiative.

## Patient satisfaction

Patient satisfaction as an outcome measure is recognised and widely used (Ong *et al.* 1995). The multi-dimensional role of the doctor-patient relationship is one of the most complex social relations (Ong *et al.* 1995), which means that this is a difficult area for research and that the results of any investigations are not well integrated. With regards to older people, few studies have looked in detail at the *reasons* behind expressed satisfaction.

In reviewing the literature in this area, Ong *et al.* (1995) identified the emergence of four variables concerning the doctor-patient relationship. These refer to: patient or doctor characteristics (Mead, 1964; Scambler, 1986); disease type and cultural differences (i.e. background variables); the content of communication and behaviour typologies (i.e. process variables) and satisfaction, recall, compliance and understanding (i.e. outcome variables).

There is reported dissatisfaction with communication (Shvartzman and Antonovsky, 1995; Eshet *et al.* 1993; Bensing, 1991) and poor compliance with medical advice is widespread (Ley, 1989; Bensing, 1991; Kirk, 1992; Inui *et al.* 1982). The factors associated with these findings are poor transmission of information (Levy, 1985; Nyamathi *et al.* 1992; Mathers and Gask, 1995), incomprehension of the information by the patient (Shvartzman and Antonovsky, 1995; Eshet *et al.* 1993; Bain, 1979) and poor patient recall of information (Ley, 1983; Williams *et al.* 1995). Problems may also occur if patients do not accept the information they are given, for example, if it contradicts with their beliefs, or if they perceive no benefits.

Attempts to address these inadequacies in communication have included studies assessing different styles and forms of communication (Ford *et al.* 1995; Reid *et al.* 1995; Clayton *et al.* 1995; Tattersall *et al.* 1994; Myers *et al.* 1994) and their

effectiveness as perceived by patients (Crawford, 1992; Dunn *et al.* 1993; Glasper and Burge, 1992; Mennie *et al.* 1992) and by health professionals (Glasper and Burge, 1992; Sherer, 1997; Davies, 1996; Dean *et al.* 1993; Hogbin and Fallowfield, 1989). Although a significant increase in patient satisfaction and decrease in anxiety was observed by most authors, these interventions were applied to selected populations in whom information provision was highly controlled, as part of the research process.

It does seem then, that the problem of patient satisfaction with medical communication is a contextual issue and that future research needs to consider the existing data from both a macro perspective of the health service infrastructure, and from a micro perspective - the impact on communication between patients, doctors, and other health professionals. Health professionals who oppose the provision of fuller information to the patients, reportedly do so because they believe such provision will lead to undesirable consequences for the patient (Ley, 1988). This paternalistic attitude is counterbalanced by findings from studies of patients' views which indicate that they do not suffer increased anxiety as a result of increased detailed information provision (Ley, 1988; Street, 1991). Indeed, many patients report improved adjustment to their condition with increased information provision (Bensing, 1991; Kojo-Austin *et al.* 1993). It is also pertinent to note that the use of coping strategies tends to be minimally explained by medical diagnosis (Felton and Revenson, 1984; Cohen and Lazarus, 1979).

Ley (1989) suggests that there are indeed grounds for optimism about the prospect of improvements in doctor-patient communication. However, there is a certain irony in Ley's observation that if the reported rate of non-compliance by health professionals is general (Ong *et al.* 1995), there is a high probability that doctors will not comply with suggestions for improved communication. The



variability of doctors own health beliefs are also demonstrated to influence their attitude towards information provision to patients.

## **Disability, rehabilitation and society**

This section provides a critical review of the contrasting ways of thinking about the nature of disability in society. The way that the WHO definitions of disability have influenced our thinking over the last 25 years is considered, along with the dominance of the medical model of disability. This model is contrasted with a more social model of disability, such as the one adopted by the Disability Rights Movement, which gives a different perspective on how disability is considered in society. People with disabilities remain at the margins of society, often depicted as pitiful or tragic characters, worthy only of the charity of their able-bodied counterparts (Imrie, 1997). Finally, the way that disability is conceptualised by health professionals in rehabilitation settings, and the way that older people, as part of a wider society, are influenced by them is considered within the existing framework of rehabilitation services for older people. This in turn relates to the way that outcome has been measured and interpreted.

## **Definitions of disability**

Definitions of disability are important. Far from being merely used for academic purposes, definitions become part of everyday thinking, and the meanings are translated not just in everyday interactions but into health and social policy. The issue of *meaning* is important in discussions of differences between the natural and social worlds and the generation of appropriate methodologies to understand these worlds (Oliver, 1996; Oliver, 1990; Oliver, 1986). In the social science literature, the debate has largely centred on the violation of meaning through the imposition of inappropriate theoretical perspectives or ignoring meaning through the collection of abstracted data (Entwistle *et al.* 1998). The area of disability

has been approached from many different perspectives, for example, interactionist (Blaxter, 1975); and Marxist, (Leonard, 1991). However, Oliver asserts that almost all studies of disability have a grand theory underpinning them: characterised as 'the personal tragedy theory of disability' (Oliver, 1986). This sees disability as something which is wholly a problem of and for the afflicted individual. Oliver argues that abstracted empiricism has proceeded from the same implicit underpinning, firstly 'by seeing disability as a problem, and then by devising methodological strategies to measure the extent of these problems that disabled individuals have to face' (Oliver, 1986).

The discourses on disability have tended to 'blame' the victim, which Imrie notes, portrays people with disabilities as inferior, dependent and by implication, of little or no value (Imrie, 1997). Such conceptions reflect what some refer to as 'able-bodied' or ableist values, that is the idea that disability is abnormal and where the goal of society is to return disabled people to a normal (able-bodied) state. In this sense disability is conceived as biologically produced and where the problems which face disabled people are the result of their physical and/or mental impairments independent of the wider socio-cultural, physical and political environments.

During the 1980's, however, disabled people provided a critique of this implicit theory to construct their own alternatives (Abberley, 1993; Oliver, 1996) and to begin to explore alternative methodological strategies. Critiques of such perspectives have emerged, trying to set physical and mental impairments in their socio-cultural contexts, to understand them less as a physiological condition but as a socially derived and conditioned state.

**The WHO definitions of impairment, disability and handicap**

The World Health Organisation (WHO) definitions are widely accepted and used in the medical and social science literature (Table 2 International classification of impairments, disabilities and handicaps). These cling to a medical classification of disability and tend to take the concept of 'normality' for granted in defining disability as 'not being able to perform an activity considered normal for a human being'. Oliver (1996) has argued that there is little consensus on what constitutes a state of normality, while the WHO's definitions of disability fail to recognise the situational and cultural relativity of how normality is understood. As long as the environment consists of social roles that are considered to be normal, the inability of the individual to live up to the requirements of these roles puts him or her in a disadvantaged position and thus creates a handicap.

**Table 2 International classification of impairments, disabilities and handicaps**

Category	Definition
Impairments	Disturbances in body structures or processes which are present at birth or result from later injury or disease.
Disabilities	Limitations in expected functional activity or as restrictions in activity due to an underlying impairment
Handicap	Difficulties in performing activities of daily living, like walking.

In this way the medical approach is conserved, since changes must be brought upon the individual rather than on the environment. Part of the problem with this concept is that it treats disability as uniform and homogenous, reinforcing the notion that there are two discreet types, the able-bodied and the disabled (Imrie, 1997), with the former leading a much more enriched existence than the latter.



**Table 3 Social stereotyping of the disabled**

Able bodies	Disabled
normal	abnormal
good	bad
fit	unfit
able	unable
independent	dependent

There has been a failure of the medical profession, and all other professions, to really involve people in a meaningful way except as passive objects of intervention, treatment and rehabilitation. This has not just trapped professionals within the medical approach, but has had oppressive consequences for disabled people:

much of the work which has been done on definitions has been carried out by people who do not themselves experience the daily problems of disability. This has directly affected the solutions, and in turn has often served to perpetuate discrimination against us, as well as wasting resources on an enormous scale

(French, 1993, p2)

A further criticism of both the WHO and similar definitions, argues Oliver, is that such definitions present disability as a static state and 'violate its situational and experiential components' (Oliver, 1996):

by trying to find strict measures of disability or focusing on 'severe' visible handicaps we draw dividing lines and make distinctions where matters are very blurry and constantly changing

(Zola, 1972, p242)

These definitions *medicalise* and *individualise* the problems of disability, and also the solutions to these perceived problems - i.e. services are also based on these individualised and medicalised perspectives of disability and are designed by

able bodied people through a process over which disabled people have little or no control (Oliver, 1986).

While this approach acknowledges that disability has a social dimension, it does not see disability as arising from social causes. Ultimately, the emphasis is on the individual person and the social dimensions of disability and handicap that arise as a direct consequence of individual impairments.

**Table 4 Survey of disabled adults - OPCS, 1986**

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Can you tell me what is wrong with you?

What complaint causes your difficulty in holding, gripping or turning things?

Are your difficulties in understanding people mainly due to a hearing problem?

Do you have a scar, blemish or deformity which limits your daily activities?

Have you attended a special school because of a long-term health problem or disability?

Does your health problem/disability mean that you need to live with relatives or someone else who can help look after you?

Did you move here because of your health problem/disability?

How difficult is it for you to get about your immediate neighbourhood on your own?

Does your health problem/disability prevent you from going out as often or as far as you would like?

Does your health problem/disability make it difficult for you to travel by bus?

Does your health problem/disability affect your work in any way at present?

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**Table 5 Alternative questions**

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Can you tell me what is wrong with society?

What defects in the design of everyday equipment like jars, bottles and tins causes you difficulty in holding, gripping or turning them?

Are your difficulties in understanding people mainly due to their inabilities to communicate with you?

Do other people's reactions to any scar, blemish or deformity you may have, limit your daily activities?

Have you attended a special school because of your education authority's policy of sending people with your health problem or disability to such places?

Are community services so poor that you need to rely on relatives or someone else to provide you with the right level of personal assistance?

What inadequacies in your housing caused you to move here?

What are the environmental constraints which make it difficult for you to get about in your immediate neighbourhood?

Are there any transport or financial problems which prevent you from going out as often or as far as you would like?

Do poorly-designed buses make it difficult for someone with your health problem/disability to use them?

Do you have problems at work because of the physical environment or the attitudes of others?

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## **The medical model of disability**

A medical model or theorisation of disability has dominated conceptions of disability in the social and medical sciences. It conceives disability as an individual, physiological condition which can be somehow treated or cured. The literature on this subject includes issues general to all disabled people, and also a body of literature on older people with disabilities.

That disability has become medicalised, there can be no doubt. Doctors are centrally involved in the lives of disabled people from the determination of whether a foetus is handicapped or not to the deaths of older people from a variety of disabling conditions

(Oliver, 1990, p48)

Oliver makes the point that some of these involvements are of course, entirely appropriate, as in the diagnosis of an impairment, the stabilisation of a medical condition, the treatment of illness occurring independently of disability and the provision of physical rehabilitation (Oliver, 1990). However, doctors are also involved in other forms of provision, including determining housing, and the allocation of financial benefits. It is not immediately obvious that doctors are the most appropriate persons to be involved.

Many professionals allied to medicine, such as physiotherapy, occupational therapy and nursing either work in organisations hierarchically dominated by the medical profession or have their professional practice structured by a discourse based upon the medical model. There have of course, been huge gains from the medicalisation of disability, in that many disabling conditions have been eradicated. But the issue for us now is not one of prolonged life expectancy, but expectation of life - what is often termed 'quality of life', and it is here that the negative and partial view prompted by medicalisation is most open to question (Oliver, 1990).

The medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual:

In order to understand disability as an experience, as a living thing, we need much more than the medical 'facts', however necessary these are in determining medication. The problem comes when they determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person who happens to be disabled

(French, 1993)

Rehabilitation services for older people, and indeed all services for disabled and older people, are organised on this model. The dominant way of thinking is related to the WHO definition (see table 2), a functional limitations paradigm, which asserts that the most significant difficulty with disability is the loss of physical capability (Imrie, 1997). This perspective argues that the disability resides with the individual, and is treatable, in that health professionals would attempt to cure a person's disease (Imrie, 1997). But with the combined effects of chronic illness, and ageism, many people are actually disabled by wider social and environmental barriers which are not treatable by medical cure or rehabilitation.

### ***Rehabilitation services in the UK***

Current rehabilitation services and their structure fit in with the dominant medical model (Wilson and Lindsay McLellan, 1997). However, current structures are not helpful to all people. Part of the problem with the dominant medical perspective is that it fails to understand how people are socialised into particular ways of being, of accepting their 'inferiority' by society and in behaving in ways which seemingly conform to the expectations and stereotypes. The notion remains that disabled people are abnormal in the sense that their impairment can be explained only in terms of deviation from a standard 'norm' and they are the problem for deviating from it (Abberley, 1993)! Yet, if the notion of abnormality is

placed in a different context, it is not disabled people, but society which fails to meet their needs:

our abnormality consists in us having a particular and large set of our human needs unprovided for, or met in inappropriate and disempowering ways

(Abberley, 1993, p111)

This notion of disability as an individual abnormality retains a powerful hold over social and medical theory. Disability is portrayed as the variable that predicts the outcome of social interaction when, in fact, the social context shapes the meaning of disability in a persons life (Fine and Asch, 1988). This perpetuates a negative image that people with disabilities are inherently 'weak' and dependent and that it is their biological condition 'rather than the environment and social context which makes one-way assistance inevitable':

it is the disability, not the institutional, physical and attitudinal environment that is blamed for role changes that might occur. The person with a disability may (initially, or always) need physical caretaking, such as help dressing, household chores, or reading. It must be asked, however, whether such assistance would be necessary if environments were adapted to the needs of people with disabilities...if technological aids were available to all who needed ... the physical environment as an obstruction remains an unchallenged given

(Fine and Asch, 1988, p6)

The origins of the idea of disability as stigma relates to Goffman's (1968) conception that stigma is a form of social branding, where individuals digress from the norms of values of society - primary and secondary deviance. The 'normalisation' theory contends that because disabled people are labelled, they are devalued (Dalley, 1991). Normalisation focuses solely on the 'role' that people occupy (Dalley, 1991), rather than on people as 'the persons that they are'. This includes the idea of social conformity - the focus is on re-modelling the individual 'as closely as possible to the functional semblance of an average



person' (Imrie, 1997). This latter point is what the entire rehabilitation service aims to do - the idea that all people should be returned to the state of fit, able bodied or as close to this as possible. This generates a context whereby the advantaged, younger, dominant groups define what is, and what is not, to be valued (Dalley, 1991; Oliver, 1996). Professional elites shape and construct the meanings of disability around technical and medical concerns, which has deflected attention away from questions of power, status and control (Trent, 1994). In response to such a situation, the empowerment model has developed as a means to empower disabled people to regain control over their lives. It's real strength is the departure from a model of functional impairment to the notion that a disabled person should have equal opportunity to maximise his or her potential and is deserving of societal help to do so (Imrie, 1997). However, this remains professionally dominated and paternalistic in that it continues to emphasise rehabilitation as the only way to achieve empowerment. Indeed the whole idea of empowerment, is limited by its failure to propose the means of combating adverse institutional attitudes and responses to impairment:

the perspective conceptualises people with disabilities as consumers, or rehabilitation clients, being acted upon, and lacking the capacity to transform their lives without the help of professional bodies... it does little to transform the hierarchical relations between professionals and disabled people, leaving the major principles and content of rehabilitation undisturbed

(Imrie, 1997 p13)

## **The social model of disability**

The contrasting approach of the social model represents disability as situated in our understanding of a wider social and political context, in the oppressive values and attitudes of society. This perspective then does not regard disability as a personal deficiency, but rather as the result of the disabling environments (Hahn, 1986; Hahn, 1988) perpetuated by the practices of the dominant institutions.

Hahn (1988) suggests that the underlying political message is the 'need to transform formerly devalued attributes into positive sources of dignity and pride and entailing self management skills and a positive self'. In this sense, the real barriers are prejudice and discrimination against people with disabilities.

However, it is also necessary to understand how attitudes are translated into actions. Criticisms of such an approach include the fact that it tends to fail to recognise that disability can take the form of a physical state, which it is important not to dismiss:

a physiological status which really negates any possibility of people with disabilities being afforded equal opportunities and treatment in that their very (physical) differences demand a difference in the way society responds to them and their (social, human and physical) needs. Indeed, the physicality of the body is often ignored in such perspectives

(Imrie, 1997, p3)

It has been suggested that an understanding of how the various components interact is vital if progress is to occur. It is necessary to recognise the changing states of bodies, of chronic illness, both physiologically and how a person feels. This stresses the temporal dimension of disability. The problems with disability are not all social. Morris (1993) has argued that the body can enable, or restrain, the pain of a disease is a physical experience with the capacity to debilitate and to reduce a person to a state of complete inability and dependence on carers. So, the importance of acknowledging the complexity of both the physiological problems and social and cultural problems which operate in dualism is stressed.

## **Summary**

The impact and problems of chronic illness are to do with the real or potential losses of identity and the way of life, and the attempt to preserve them as much as possible. Charmaz (1983) comments however, that the language of loss is

not common to *all* individuals who are strikingly ill and she notes that a striking contrast was apparent among people she studied whose condition had improved and who were, as a result, able to feel hopeful. This observation is an important one when we come to examine the impact of chronic illness on older people and how they conceptualise outcome.

The literature on coping with chronic illness is extensive, but incomplete. Little evidence exists from collaborative studies about the relationship between information provision and outcomes. Although each of these features of health care have been independently investigated, they are mutually inclusive and require simultaneous scrutiny, to improve patient satisfaction with health care, to inform the future training of health professionals, to develop communication between health professionals, processes of empowerment and participation and to develop approaches to person-centred outcome measures. There has been a significant shift towards a greater psychological understanding of coping with chronic illness. Unfortunately, the evidence indicates that this enlightenment has not greatly improved professional-patient communication. By considering the empirical evidence of health cognitions on both patients and professionals, it transpires that there is a dearth of information about professionals' own health beliefs and how these may impinge upon their attitudes towards and communication with patients. Patients' views on information needs, particularly those of older people, are under-represented. Qualitative approaches to data collection could be used to establish reliable data on the views of older patients. Professionals are reported to value the ideal of an 'informed' patient, but display reluctance to attach equal status to information provision, diagnosis, treatment and care decisions. This review indicates a need for further in-depth investigation of these concepts, including the current status of information provision in chronic illness, from the patient's perspective, along with issues



surrounding communication, participation, decision-making, empowerment, and satisfaction.

The different theories of disability are, in their own ways, reductionist and unable to do justice to the multidimensionality of disablement (Imrie, 1997). The biomedical perspective, with its emphasis on the physical and impairment and the need for a medical response is still a powerful underpinning of official attitudes and responses to disability. It tends to reinforce the notion that the body must be 'fixed' to fit the environment, thus emphasising cure and rehabilitation. This underpins services for older people with disabilities and is part of the underlying philosophy behind the development of the majority of outcome measures.

Social models tend to imply that if investments are made in modifying the environment and in getting information to disabled people, lives may be transformed. This does not necessarily follow, as this does little to address the underlying values of society and structures in which disabled people have to lead out their lives. Social models can also appear idealistic: how, for example, does society meet the needs of people with cognitive impairment given the challenge to meaningful understanding of their beliefs and needs?

There is little literature on what older people value, and where individuals gain meaning from. The lived experience of disability for older people is a neglected area, but may be extremely important in helping to identify how they conceptualise outcome and what outcomes of their health and social care they as individuals, and as a wider group, may desire. Given that a medical model of disability dominates the development of many outcome measures, perhaps especially a functionalist perspective, it is vital to ensure that the perspective of

older people is explored, and that their values are central to the development of approaches to person-centred outcome measures.

## Chapter 5

### Outcomes in health services research

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We must examine the successive succession of events from which the antagonism has sprung in order to discover in the conditions thus created the means of ending the conflict

(Engels, 1884, p175)

#### Why measure outcome?

Health status and health outcome measures are becoming increasingly important in order to assess the quality of care provided for patients (McColl *et al.* 1997).

Outcomes have achieved a high profile in recent policy discussions following the emphasis on health gain introduced in the Health of the Nation, and assessment of health outcomes has been pushed to the centre stage of the NHS (Brettle, 1995). Information on outcome is required by all levels and sectors of the health service - outcome data is sought after by many purchasers who include outcomes criteria in their contracts as a means of assessing effectiveness (Davies and Crombie, 1995). Providers must know whether the outcome of treatment is beneficial or not in order both to meet the contracts and to ensure high quality service provision. For individual clinicians, nurses, physiotherapists and other practitioners, outcome measurement is an integral part of routinely monitoring the progress of individual patients and is used to establish a reliable basis for clinical decision-making. Outcome measurement is also high on the research agenda to identify opportunities for improvement and is 'a field that is undergoing rapid development and expansion' (Brettle *et al.* 1998).



Wattis *et al.* (1994) have suggested that information on outcomes is needed to describe in quantitative terms the impact of care in patient's lives; to establish a reliable basis for clinical decision-making by clinicians and patients; and to evaluate the effectiveness of care and to identify opportunities for improvement. However, what the patient actually wants or how people conceptualise outcome is often an unknown entity. The sheer volume of instruments presents the potential users with a problem of which measures to select. It is apparent that many instruments, especially those with a 'track record', are sometimes used in inappropriate situations or under conditions in which the measure could not be reasonably expected to give a useful and reliable answer. There are a number of dangers in such misuse. An instrument that is perfectly adequate when used as intended may be afforded an unfairly adverse reputation. Costly resources may be devoted to a useless data collection exercise. Users may be dissuaded from continuing with health outcome assessment because they encounter problems with administration, analysis or interpretation of data. Most dangerously, inappropriate choice and application of measures may yield an apparently plausible, yet fundamentally flawed answer, leading to inappropriate decisions or actions for patients, health services or society at large.

In this chapter some of the important issues in designing, appraising and choosing instruments to assess health status and measure outcome are discussed, along with some of the conceptual, theoretical and practical issues.

Structure, process and outcome

Donabedian and Rosenfeld (1961) separated the components of health care into structure, process and outcome (Table 6 Taxonomy for quality assessment), and described outcome as:

a change in a patient’s current and future health status that can be attributed to antecedent health care

(Donabedian, 1980, p256)

Table 6 Taxonomy for quality assessment

Category	Definition
Structure of care	the resources available to those undertaking the health care to be assessed
Process of care	the activities undertaken by the providers whose health is being assessed
Outcome of care	the changes in the patients’ health status and welfare resulting from the health care that is being assessed

Table 7 Definitions of commonly used terms

Category	Definition
health status	a snap-shot view, the ‘state of health’ at a given point in time
outcome indicator	a measure of health used quantitatively to describe the health of a group of people at a particular time point
outcome measure	a measure of health used over time to attribute changes to a particular intervention
outcomes management	taking the information provided as a result of measuring and monitoring outcomes and applying it to improving the quality of care

Shanks and Frater (1993), in the absence of a consistent definition of outcome attempted to clarify the concepts and devised a hierarchy of four key terms in outcome assessment (Table 8 Taxonomy of outcomes ).

Table 8 Taxonomy of outcomes

Category	Definition
outcome	a result or effect
health outcome	an effect manifest in health status
health care outcome	a result which is evident in attributable and responsive to health care
health outcome of health care	a result evident in terms of health status which is attributable and responsive to health care

Although there is by no means consensus over these terms, they have become widely accepted as a framework for exploring the complexity of the variables which impinge on the outcome of care for an individual. However, some authors now suggest that these definitions are too detailed (McColl *et al.* 1997), and unnecessarily complicate the debate.

Clinicians who previously focused on the *structure* of care (the staffing and other resources, skills and infrastructure) and biomedical indicators and the *process* of care (what is actually done) have shifted emphasis on to the evaluation of health *outcomes*. Brettle *et al.* (1998) suggest that a working definition of outcome is the attributable effect of an intervention or its lack on a previous health state. A number of important points follow from such a definition. Firstly, a statement of outcome requires either evidence of a known process-outcome link, causality or a likelihood of plausibility of such a link. The key point, then, is *proof of attribution* - how to determine whether changes are the result of the intervention



or whether they would have happened over time anyway. However, attribution is not always an 'either-or' concept but a matter of degree (Shanks and Frater, 1993). Secondly, if a causal link is known then it may be sufficient to monitor process itself, on the assumption that if the process is undertaken appropriately then the expected outcome will follow. At the same time, the occurrence of possible adverse events need to be monitored with a view to a subsequent audit or evaluation as to *why* expected outcomes were not achieved. There is distinction between intermediate and final outcomes, or short term and long term. The idea of outcome implies measurement at more than one point in time. Outside of laboratory setting and highly controlled clinical trials, however, there are major difficulties in controlling for confounding factors, such as the social and environmental conditions, and therefore attributing observed variation in a persons health to a specific process of care or intervention is extremely problematic. For this reason, for many for many so-called 'health outcome measures', there is little hard evidence of responsiveness to change over time following an intervention.

There can be a number of influences on a persons health, only some of which are related to the care received (McColl *et al.* 1997). For example, a person may indulge in risk taking behaviour despite information provided about that risk. A key element is providing feedback to clinicians or to other users in appropriate form to enable them to translate the results into action. However, there are inevitable limitations of this approach. Outcome data is measured relative to the contribution made by the health care setting, for example a hospital. They represent marginal health benefit to the patients receiving care in those settings and there are tenuous links between the treatment effects and patient health. It is difficult to prove that the results would have happened anyway if the patient had not received treatment. Considerable ambiguity exists about the methods

and purpose of outcome measurement. The terms can embrace a number of distinct methods in different contexts as Donabedian points out:

patient outcomes are an immensely complex construct. They span the range of results that proceed (or are presumed to be associated with) the provision of health care services. They are measured both directly and indirectly over differing periods of time and with varying degrees of objectivity, reliability and validity

(Donabedian, 1989, p38)

The situation is further complicated by the changes in demographics and the emergence of effective treatments and preventative strategies for many acute conditions has led to a shift in focus from acute conditions to chronic conditions. For the majority of people with chronic illness, a significant proportion of whom are older people, a cure is not a realistic option and the aim of health care becomes to manage a care to achieve the best 'quality of life' or slow the natural deterioration. In rehabilitation settings for older people, multi-disciplinary teams may be seeking to manage care and treatment for a range of conditions. Generally speaking, the interest in clinical settings in the health outcome of interventions have traditionally been linked to the belief that it is possible to make people healthy again simply by eliminating their diseases. Chronic diseases, for which there is no cure, challenge these assumptions. The outcome measures or instruments which are developed to measure change must be sensitive to the levels of change expected, otherwise change will not be detected. Therefore, well established measures which are useful for screening or profiling a population may not be suitable for measuring changes over time (Fitzpatrick, 1996).

## **Medical and social models of disability**

Central to the biomedical model is the belief that through science and technology human life will be improved. The science and humanism of medicine is therefore perceived as largely beneficial and progressive in understanding and responding



to illness and disease (Bond, 1997). A major concern of this approach is the loss of 'normality' experienced by people with chronic illness and the impact of the condition on friends and family. Oliver (1990) has referred to this as 'personal tragedy theory', with the associated labelling of people as 'victims' or 'sufferers'. A consequence of this approach has been the individualisation and medicalisation of illness (Bond, 1992), processes which lead to the blaming of the individual (Oliver, 1990) and the loss of personhood (Kitwood, 1997).

The observation of wide medical practice variations has prompted a variety of studies to examine the relationship between variations in process and the resulting outcomes. Some of the alternative strategies adopted to examine this question and distinguish between studies according to the level of data collected have been identified, ranging from cross sectional studies using hospital discharge abstract data to more detailed prospective analysis of longitudinal cohorts of patients.

### **Normative approach to measurement**

The normative approach is rooted in functionalist social science, and is driven by the values and perspective of younger, white, middle-class, male, clinicians and researchers. Scientific or positivist approaches to method dominate. There is claimed to be an advantage in using standardised instruments, typically patient completed questionnaires, to assess general health from the patients perspective and to improve doctor -patient communication. However, many clinicians remain unconvinced as to the use of the value of these tools (Nelson *et al.* 1990).

Almost 50 years ago, the WHO defined health as 'a complete state of physical, psychological and social well-being and not just the absence of disease' (World Health Organisation, 1980). Since this definition was formulated, health has become increasingly conceptualised as multidimensional, and over the past



several decades a vast number of instruments have been developed to measure health in the broadened sense outlined by WHO. With these instruments, the assessment of health status (also referred to in the literature, as 'subjective health status', 'quality of life' or 'health related quality of life') has become a popular and important method for evaluating the effectiveness of health care interventions (Jenkinson *et al.* 1994).

The evaluation of health care using health status instruments reflects a movement away from the medical professions traditional definitions of health, which used to be defined in terms of death and extent of morbidity and towards a much broader view which recognises its dimensionality (Ware, 1987). Before the 1970's, health care investigators were content 'to focus on either major morbidity and mortality or on measures of physiological function or patient functional performance' to justify therapeutic interventions (Guyatt and Cook, 1994,p 630). Although the bias of scientific medicine has been to prefer objective test results over subjective reports by the patients themselves, there is a growing interest by physicians and researchers in considering patients point of view about treatment and outcomes (Albrecht, 1994). To facilitate this interest, health status instruments designed to measure the patients views of their health, now exist in abundance (O'Boyle, 1994; O'Boyle *et al.* 1994; Ruta *et al.* 1994). Such instruments are said to offer a reliable, valid, and above all, independent method of assessing the impact of health care interventions (Jenkinson *et al.* 1993). They can be used to measure individual's or population's health and the benefits and harms that can come about from different forms of health care (Fitzpatrick *et al.* 1998).

There are currently many instruments available to measure subjective health status (McDowell and Newell, 1987; Bowling, 1996; Bowling, 1995). Most of the literature has tended to focus on patients satisfaction with health care, on

psychiatric function and functional ability at the expense of considering other variables.

## **Psychosocial functioning: quality of Life (QOL)**

Assessments of psycho-social functioning have essentially been concerned with measuring what has since come to be referred to variously as 'quality of life' or 'health-related quality of life'. In other words, with investigating the impact of a person's condition and the proposed treatment on non-clinical aspects of their functioning. Recently in the quality of life literature, the more precise term 'health-related quality of life' has gained preference over 'quality of life', following upon recognition that health or lack of it constitutes only one, albeit an important element in a person's overall quality of life (Torrance, 1986), and may be mediated by other factors.

The term 'quality of life' is not a new one, but is a relatively recent addition to clinician's frame of reference and vocabulary. A number of different conceptual approaches to quality of life have contributed to current understanding and to the way in which efforts are made to measure it. One problem in the quality of life literature is that the term 'quality of life' is used interchangeably with 'health status'. There is little consensus over definitions and terminology. Bowling (1996) comments that it is becoming increasingly fashionable to equate all non-clinical data collected in studies of illness and treatment for illness with 'quality of life', though few in fact undertake a comprehensive quality of life assessment.

Quality of life assessments are now seen as relevant to clinical decision-making in that they provide information about the degrees to which disease and the treatment of disease enhance or detract from a person's ability to function, physically, socially and psychologically; to apply the terminology of the WHO classification (World Health Organisation, 1980) they are concerned more with



disability and handicap than with impairment. A major problem in trying to assess quality of life within this or any other framework is that we are trying to quantify constructs that are not always directly measurable (Johnson, 1994). Within the normative approach, researchers have focused their efforts to try and find a way of measuring the seemingly unmeasurable; whether using single questions or multi-items scales, generic or disease specific measures, 'the process must satisfy the key universal requirement of a scientific instrument, that is, it should be valid, reliable, sensitive to change, and above all, practical' (Johnson, 1994,p66). Precisely which aspects of QOL researchers choose to focus on or emphasise will depend on the condition under study and the nature of the investigation. This latter will also determine to a large extent the methodology adopted to make QOL assessment.

Historically, because QOL assessment was concerned with the apparently unmeasurable, it was considered to yield scientifically 'soft' data, of little value to clinicians and even now many practitioners exhibit enthusiasm for the potential relevance of QOL measures but at the same time express a number of unresolved doubts (Fitzpatrick *et al.* 1998). However, Fallowfield (1994, p96) contends that many of the measures for quality of life look 'equally hard, if not better than some of the more orthodox measures'. Fallowfield (1994) contends that as long as the basic scientific principles are applied, the evidence that QOL can make an important contribution to the evaluation of different treatments and so represents a valuable aid to clinical decision making.

Five concepts which have contributed to current understanding of the concept 'quality of life' have been identified (Fallowfield, 1994). These they list as the psychological view; the time trade-off or utility concept; the community centred concept; the reintegration concept and Calman's gap principle .



*The psychological view:* reflects the distinction between illness and disease.

Whereas physicians concentrate on the disease process, patients are concerned with the experience of illness, and many factors contribute to this experience (chapter 4). This view also emphasises the relationship between physiology and psyche, and the fact that these two are not independent of each other.

*Utility or time trade-off concepts:* reflect the fact that some individuals prefer survival at any cost, while others do not consider life worth living under certain circumstances. Some people may be prepared to trade off a proportion of their full life expectancy to avoid disability and impaired quality of life. Schipper notes that patients make such trade-offs all the time as they seek to maximise their quality of life in the face of ill health.

*The community-centred concept:* originally proposed by Ware (Ware, 1998), provides a sense of the impact of illness on the broader community, since illness affects the quality of life of more than just the ill person - its impact on other family members, as shown in an earlier chapter, being a case in point. In Ware's conceptualisation, variables are grouped in five concentric circles, with physiological parameters of disease in the centre, and social and role functioning on the outside. General health perceptions occupy the fourth circle out, because Ware considers them to encompass a person's evaluation of the preceding three, though the correspondence may be far from perfect.

*Reintegration into normal living:* has been proposed by Williams and Wood (1988) as a proxy concept for quality of life, and concerns the reorganisation of physical, psychological and social characteristics of any individual into a harmonious whole, so that well adjusted living can be resumed following the advent of illness. They comment that it is an appropriate measure for treatment outcome in chronic disease where patients have to learn to live with the

condition. This concept of regaining harmony has some parallels with the notions of biographical disruption and reconstitution of self (Bury and Holme, 1990) discussed in chapter 4.

*Calman's gap principle:* focuses on the gap between an individual's expectations and achievements. The smaller the gap, the better the quality of life. Calman (1984) showed that the size of the gap may vary over time, as a patient's health improves or deteriorates; and the impact of illness will vary depending on the patient's perception about his quality of life at the time of the diagnosis. It has been argued that increasing a person's coping skills may reduce the gap between how things are and how he would like them to be and thus may improve his quality of life.

What has emerged from consideration of these various attempts to conceptualise quality of life is a functional definition that is measurable and evaluative over time, rests on the person's own perspective and consists of four broad domains: physical and occupational function; psychological state; social interaction; and somatic sensation. They take issue with the addition by some authors of a fifth domain, the financial consequences of illness, which is they argue, dependent on the structure of community social support programmes rather than the biology of the disease. Their functional definition rests on the premise that the goal of medicine is to make morbidity and mortality of a particular disease disappear. Historically, quality of life measurement can be seen as a reflection of the shift in medical preoccupation during the last century from acute to chronic disease. It is concerned with evaluating the effectiveness

of medicine to control rather than cure disease:

The rising expectations of the past 150 years have led to a shift from viewing health in terms of survival, through a phase of defining it in terms of freedom from disease. Thence to an emphasis on the individual's ability to perform his daily activities, and now to the current emphasis on positive themes of happiness, social and emotional well-being and quality of life

(McDowell and Newell, 1987, p14)

During the 1940's the World Health Organisations definition of health as 'not only the absence of infirmity and disease but also a state of physical, mental and social well-being' laid the foundation to and was the catalyst for the attention to be given to quality of life. At the time, few clinicians had recognised the importance of measuring wider than clinical variables, and the real impetus came from social scientists who had been focusing on quality of life for decades.

The considerable terminological confusion in the literature has focused largely on the distinctions between 'health status', 'quality of life' and 'health-related quality of life'. Patrick and Erickson (1993) argue that the more specific term 'health related quality of life' is preferred since not all dimensions are necessarily health or medical concerns. However, there is still debate over exactly what 'health related quality of life' covers - whether it is limited to aspects of physical functioning and emotional status, or whether it involves health perceptions; functional status; or impairment. Guyatt *et al.* (1993) comment that though clinicians now tend to use the term 'health related quality of life', when patients are ill almost all aspects of life can become health related. In light of all this, there is a lot of merit in the argument that we should first have been explicit about our selection of domains and dimensions and state why we consider them relevant (Brooks, 1991).



## Measuring quality of life

A number of authors have made the case for measuring quality of life. Katz and Stroud (1989) list among the uses of QOL assessment: the provision of normative data for policy making and planning; provision of information for development of quality assurance standards; provision of information for use in developing new models of care; and in the context of public debate about the allocation of limited medical resources. Guyatt *et al.* (1993) argue that QOL measurement has become important because although physiological measures provide important information to clinicians, they are often of little interest to patients. The emphasis on the technological and scientific aspects of medicine without regard to the wider needs of people has led Fallowfield (1990) to describe quality of life as 'the missing measurement in health care'. Levin (1998) cites a number of reasons for measuring it. These include that traditional measures of outcome are of little or no help in making judgements about chronic conditions; new technologies, such as organ transplantations, raise questions as to what kind of life is being prolonged; the importance of examining costs and benefits of alternative treatments; and cultural and philosophical developments have led to a criticism of a solely biomedical model in health care and scepticism of the value of health interventions, emphasising a more holistic approach to health care provision and assessment.

In a series of articles in the British Medical Journal (Fitzpatrick *et al.* 1992; Fletcher *et al.* 1992), Fitzpatrick and his colleagues have proposed a number of different ways in which QOL measures can be applied. They comment that QOL measures have been shown to be better than conventional clinical ones as predictors of long term outcomes in rheumatoid arthritis, and are therefore valuable in identifying 'at risk' individuals. Despite these findings and the growing popularity of QOL measurement, these authors point out that QOL information

does not yet generally appear to alter clinical decisions or changes in health status.

### **Methodological and practical issues in assessing QOL**

In addition to the philosophical and terminological issues, there are a number of methodological issues in assessing quality of life including: from whom should such data be collected; what dimensions of quality of life are important; which instrument is appropriate to measure these dimensions; is the instrument psychometrically sound; and what are the practical considerations in attempting to assess QOL?

#### **From whom should QOL information be collected?**

Some of the earliest 'quality of life' and 'health status measures' such as the Barthel Index (Mahoney and Barthel, 1965) were designed to be completed by physicians or other health professionals. It is now generally agreed that what constitutes a good quality of life is a personal and individual question, and judgements about the way that illness and treatments impact upon it should be made by individuals themselves. The essence of quality of life assessment is to examine the person's subjective viewpoint, so the respondent, wherever possible, must be the patient.

#### **What dimensions should be measured?**

There is wide variation between authors as to what constitutes core domains. Spitzer (1987) suggests that any QOL assessments should, at a minimum, consider physical function, social function, emotional and mental state, the burden of symptoms and a sense of well-being. Fallowfield (1994) lists four core domains. Hermann (1992) adds locus of control, spiritual well-being and stress to these four core domains. Deciding precisely which dimensions of QOL to

measure will depend on a number of factors, including the nature of the population under study, the nature of the condition, predicated costs and benefits of treatment and the length of observation time (Cox *et al.* 1992). It will also depend on the availability of suitable instruments and the environment in which the measurement will be conducted.

### ***Appropriate instruments***

Seven major types of instrument can be identified in the literature: disease-specific, site-specific, dimension-specific, generic, summary item, individualised, and utility (Fitzpatrick *et al.* 1998). There are a daunting array of outcome measures and instruments facing researchers and clinicians. A number of publications deal with the subject of selecting both generic and condition-specific health status and health outcome measures (Wilkin *et al.* 1992; Bowling, 1996; Bowling, 1995; McDowell and Newell, 1987; Fitzpatrick *et al.* 1998; McColl *et al.* 1998). Substantial reviews have also emerged of outcome measures for specific groups - older people or stroke patients (Rodgers *et al.* 1993; Wade, 1992; Wade, 1992). These publications cover the great number of instruments which have been developed covering functional status; physical health, mental health, social functioning, role functioning and patient satisfaction (Cleary *et al.* 1993; Fitzpatrick, 1990). The past few years have seen a growth in the acceptability and application of measures which attempt to define general health status

### ***Generic instruments***

Generic instruments, which include both health profiles and utility measurements, are applicable in a wide variety of populations because they cover the complete spectrum of function, disability and distress that is relevant to quality of life (Guyatt *et al.* 1989). Generic measures cover areas of physical, social and psychological function. Health profiles are designed to measure a number of dimensions of health status. Utility measures, derived from economic and



decision theories, assign a single number to health related quality of life. These instruments can be used to provide data for use in economic evaluations in health care. Generic measures of health status such as the Nottingham Health Profile (Hunt *et al.* 1980) and the SF-36 (Ware, Jr. and Sherbourne, 1992) have been held up as 'gold standards' (Spitzer, 1987). Generic instruments such as these are said to be 'broadly applicable across types and severities of disease, across different medical treatments or health interventions, and across demographic and cultural subgroups (Deyo and Patrick, 1995). They are designed to cover the complete spectrum of function, disability and distress relevant to quality of life (Guyatt and Jaeschke, 1990). Their supposed value is that they are reported to have established psychometric properties and allow comparisons to be made across different populations and clinical conditions. Their major disadvantage is that they may be insensitive to specific problems and give no opportunity for the individual to express the meaning of their circumstances or what is important to them.

### ***Condition or disease specific instruments***

Condition or disease specific instruments differ from generic measures in that they focus on particular aspects of health status, and can be specific to a disease, to a population of patients, to a certain function, or to a given condition or problem (Guyatt *et al.* 1989). Bowling (1995) makes a further distinction between domain and condition specific instruments. She considers measures that assess a certain function to be domain-specific and gives examples of self-esteem and psychological function. Condition specific instruments are often used alongside generic measures in order to more fully document patient health status. Supplementing generic instruments with condition and domain specific instruments represents a more comprehensive approach, since it can provide

information on the major domains common to all diseases, as well as on the unique aspects of the particular condition of interest (Guyatt *et al.* 1989).

### ***Index, profile or battery***

In QOL measurement, the term index is used to denote a single number which may be derived from a single question or from a scale or series of scales; a profile refers to a single instrument which provides separate scores for two or more components of quality of life; a battery is an assembly of a number of different instruments selected to provide information on multiple components of QOL. All pose a problem of interpretation, if different groups of patients fare better on some scales and worse on others. The problems with indices is that they may condense information to the point where sensitivity is compromised.

In conceptualising health and defining appropriate outcomes, consideration must also be given as to whether the emphasis should be on 'positive' aspects of health, such as well-being, or on 'negative' aspects such as anxiety, depression or functional limitations. The WHO definition of health (see chapter 4) represented an ideological move towards the concept of 'positive health' and it would appear that a majority of measures have tried to respond to this challenge. This has corresponded with a shift in emphasis from symptoms, and disability to quality of life, such as the quality of life well being scale. However, some authors suggest that the actual content and conceptual basis of the instruments have changed rather less than the names imply (McColl *et al.* 1997)! Wilkin and colleagues also argue that there are significant methodological barriers to developing measures based on the concept of 'positive health' (Wilkin, 1986). They argue that if 'positive health' is defined in terms of achievement of individual potential, it can only be conceptualised in terms of each individual respondent's own definitions. While some developers have attempted to meet

this challenge, the vast majority of instruments do not incorporate such an individual perspective.

Even when a number of instruments ostensibly tap the same concept, the wording of items may result in measuring very different things. This is best illustrated by the difference between Activity of Daily Living Scales; the questions of ‘*can you*’ and ‘*do you*’ may illicit information on judgement or reported behaviour respectively.

## **Psychometrical considerations**

Fitzpatrick *et al.* (1998) specify that measures selected for use in clinical trials must be considered in terms of appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility. What is meant by these terms is addressed in details in all the standard textbooks on outcome measurement (McDowell and Newell, 1987; Bowling, 1991). However, these criteria are not rank ordered in terms of importance and they do not follow any sequential logic in terms of how they should be approached. A further difficulty is that none of the criteria are explicitly defined and there are different definitions of each term.

Since instruments used in clinical practice and research discriminate among individuals or groups of patients, to predict outcome or prognosis and to evaluate within-patient change over time, a basic requirement has been that they are valid, reliable and responsive (Guyatt and Jaeschke, 1990). However three of the criteria, appropriateness, precision, and interpretability are increasingly discussed in the literature but are much less likely to feature in standard check lists in many discussions (Fitzpatrick *et al.* 1998). This reflects the dominance of a normative approach and an over emphasis on psychometrics.



### ***Relevance and appropriateness***

The first and absolutely fundamental consideration to be faced by clinicians and researchers when selecting or developing person-centred outcome measures is how to identify if it is appropriate. Linked to this is the question: appropriate to whom? For example, the question: is the content of the instrument appropriate to the question which the clinical trial is intended to address? (Fitzpatrick *et al.* 1998) is subtly different to 'does the instrument contain domains which are relevant and appropriate to the patient or person involved?' This latter point is particularly significant. Measures of outcome used in trials and intended to assess the patient perspective are often limited or superficial. They tend to reflect the values of the developers, often white, professional, male individuals and do not necessarily reflect the views of the person. If this fundamental issue is not adequately addressed, then all the other factors become questionable.

### ***Validity***

Validity is concerned with whether or not an instrument measures what it purports to measure and is related to other variables in previously hypothesised ways.

There are a number of different aspects of validity, including *content validity* (does the instrument cover the full range of relevant topics?) and *construct validity* (does it relate to other measures in a manner consistent with previously constructed theoretical hypotheses? - for example, does it distinguish between different patient group, or groups of patients with differing disease severity?).

Validity shown for one purpose can not be assumed for all applications or populations (Fitzpatrick *et al.* 1998). The validity of a quality of life instrument is often difficult to establish, by virtue of its essentially subjective nature (Fitzpatrick *et al.* 1998).

***Reproducibility or reliability***

This is concerned with the ability of an instrument to produce the same results on repeated occasions under similar test conditions. If the reliability of the instrument is unknown, then any improvement or deterioration in a patient following a change in treatment or the nature of health care might incorrectly be attributed to that change, when it is in fact due to chance factors (Fallowfield, 1990). Reliability is generally assessed in one of two ways: by examining its *internal consistency* (the level of agreement at a single administration, for all dimensions, for equivalent halves of the sample); and by examining its *test-retest correlation's*, when administered to the same population on two separate occasions. There are problems with this latter approach in that if the time between the two administrations is too short, respondents may recall their earlier answer so that the true reliability of the measures will be over-estimated; and if too long, changes in disease state and progression may cause a change in test score which could be interpreted wrongly as a reflection of its poor reliability (Fallowfield, 1990).

***Responsiveness***

This concerns the ability of the instrument to detect clinically significant changes over time. Though unimportant for cross-sectional studies, it is a crucial requirement for clinical trials and evaluation research and one which can be problematic, since often the only available framework for examining the property of an instrument is in the trial in which it is being applied! This can mean that if at the end of a trial no change is detected, the lack of change may represent either a treatment failure or the failure of the instrument to detect those changes that have occurred. Among the reasons why an instrument may be insensitive to change are: that it includes items which are not relevant or appropriate for a particular disease or a group of patients; that it includes items focusing on areas



where change would not be predicated; that it fails to include items which are sensitive to subtle, but important changes for patients (Fitzpatrick, 1999). The choice of one instrument over another apparently measuring the same dimensions can have considerable effect on the results obtained because of their differing levels of sensitivity: for example, Fitzpatrick *et al.* (1998) compared sensitivity to change over time of four health status measures among patients with rheumatoid arthritis, and found that no single instrument consistently showed the most change across all dimensions.

### **Practical issues in outcome measurement**

In addition to theoretical and methodological issues, there are a number of practical problems in current outcome assessment which need to be resolved, including how and when to administer the selected instrument, and to which patients. Cox *et al.* (1992) point out that a patient's response to an assessment may vary according to the physical context in which it takes place - at home, in the hospital clinic or in a neutral environment. Different possible modes of administration of assessments are by semi-structured or structured interview, by self-completion, including postal questionnaires, and by telephone, though the latter has been shown to be less sensitive and is particularly subject to bias since some sections of the population will be under-represented (McColl *et al.* 1997). Guyatt *et al.* (1993) have compared the strengths and weaknesses of the various approaches. There are advantages and disadvantages to each and the choice will ultimately rest on factors such as the design of the study and the available financial and manpower resources. One advantage of interviews is that they elicit a significantly higher response rate. Conversely, interviewers can introduce biases if not properly trained - an expensive and time-consuming task. The length of time required to complete the assessment is also a very relevant



consideration, particularly among subjects who are ill or infirm. Very lengthy interview schedules or self-completion questionnaires may reduce the likelihood of achieving a good response, though there is some evidence that response to postal questionnaires are unaffected by their length.

## **Person-centred approaches to evaluating outcome**

Patient-based outcome measures or person-centred outcome measures is a short-hand term referring to the array of questionnaires, interview schedules and other related methods of assessing health, illness and benefits of health care interventions from the patient's perspective (Fitzpatrick *et al.* 1998). Person-centred outcome measures addressing constructs such as health-related quality of life, subjective health status and functional status are increasingly used in clinical research (Fitzpatrick *et al.* 1998).

## **Person-centred approaches to quality of life assessment**

Ruta *et al.* (1994) argued that a truly valid measure of outcome would be one that allowed patients to focus on those aspects of their lives which they considered to be of greatest importance, and to rate the extent to which those most important aspects were affected by their condition. These authors developed what they refer to as a patient-generated index of quality of life (PGI), drawing on techniques developed by Guyatt *et al.* (1993). The PGI is completed in three stages. In the first, patients are asked to list the five most important areas of their life affected by their condition. In the second, they are asked to rate on a scale of 0 to 100 how badly they are affected in each of their chosen areas. In the third stage, patients are asked to imagine they can improve on some or all of the chosen areas of their life; they are given points that they can choose to spend across one or more of the areas; the points they allocate in each area represent the relative importance to them of potential improvements in that area.

Patient's overall score on the index is the summed product of their scores at stages 2 and 3. The index is thus intended to represent the extent to which reality falls short of patient's hopes and expectations in those areas of their lives where they would most value improvements.

Ruta and his colleagues applied their patient-generated index to a population of patients with low back pain of an acute nature. They assessed the validity of their approach by comparing patient's scores on the PGI with their responses on a well-validated generic health status measure, the SF-36 (Ware, Jr. and Sherbourne, 1992), and their scores on a clinical back pain questionnaire, with which they showed high correlations. The authors concluded that the PGI offers an exciting new approach to the problem of measuring quality of life with considerable potential for use in a wide range of clinical conditions for which the measurement, valuation and comparison of outcome has hitherto proved very difficult. A notable limitation of their approach, however, is that when used in its self completion form, response rates are somewhat less impressive than when it is interviewer administered. Of the 777 patients to whom the questionnaire was sent, 74% returned it, but only 446 had attempted to complete the PGI, and of these, only 359 succeeded in completing it correctly (63% of all respondents). The 37% of respondents who failed to complete the PGI were significantly less educated, more likely not to own their own homes and had poorer physical functioning.

O'Boyle and colleagues (1994) have also attempted to develop a method of assessing quality of life in individual patients which they call the 'Schedule for the Evaluation of Individual Quality of Life', or SEIQoL. Their approach is based on the theory of judgement analysis and is conceptually distinct from that of Ruta *et al.* (1994) in that patients are asked to list the areas of their lives which are most affected by their clinical condition. Subjects rate their current status in each area



against a visual analogue scale ranging from 0 (as bad as could possibly be) to 100 (as good as could possibly be). To quantify the relative weight of each elicited area, subjects are presented with a series of randomly generated profiles of hypothetical people and asked to rate the QOL score they associate with each profile. An overall QOL score for each individual is then calculated by multiplying their current self-ratings by the calculated weights and summing their products. The advantage of SEIQoL over the standard approach to QOL assessment is, argue the authors, that weights assigned to particular areas are theoretically independent and so can change independently. It is also they maintain, applicable across all patients, illnesses and diseases and is not culturally specific. However, the authors accept that its disadvantage is that compared to standardised QOL questionnaires, it is cumbersome both to administer and to complete.

### **Outcome measures for older people in rehabilitation settings**

The development of outcome measures for older people is in some ways less well advanced than other groups. For example, many clinical trials specifically exclude older people (McColl *et al.* 1997). There are a number of studies which have sought to evaluate care of older patients by examining particular institutional settings for care. For example, the effectiveness and efficiency of day hospital care has been examined (Donaldson *et al.* 1987) and compared to other settings. Other studies have focused on specific disease groups e.g. stroke (Forster and Young, 1992).

The medical classification of older people is difficult because older people can typically suffer from a number of different disease conditions. Key issues include improvement or maintenance in chronic conditions. Given the complexity of the medical problems, it appears that in care of the older people the types of goals



for most patients tended to be assured to be similar despite differences in the nature of the underlying medical conditions. Identifying expected changes in health is difficult because of a lack of theoretical and empirical work on how older people conceptualise outcome.

The principle of this study was that for any method of assessing outcomes for older people, the domains included must be relevant and appropriate to the group in question; i.e. the content of the instrument must be grounded in the views of older people to ensure it reflects their perspective. A further principle is that methods must not only reflect the *content* of people's views, but also crucially the *form* of peoples views. It is the latter that presents a particular challenge to researchers in this field (Long, 1994).

### ***Goal Attainment Scaling***

In the field of rehabilitation for older people, a patient-generated approach which has gained increased recognition from researchers and clinicians has been a goal-oriented approach. Developed by Kirechuk (Kiresuk and Sherman, 1968) and further developed by Rockwood and Stolle (1997) in Canada, goal attainment scaling has been in clinical practice in a limited number of settings for some years. It has recently been taken seriously as a method of assessing outcomes following a health intervention. The approach allows a systematic method of identifying the potential range of problems, the development of a patient-oriented strategy for addressing these, and a method of measuring the effect of treatment interventions. Rockwood (1994) recommend that the goals should be appropriate for the individual, explicit, have practical guides to action, be attainable but challenging, and importantly shared. Once goals are established then criteria must be set in advance for each goal. Ideally there would be between four and seven goals per patient. Goals should be rated from minor to major with definitions of the follow-up time period. Goals should be set

formally with clear criteria for success. A follow up goal achievement is rated and a goal attainment score calculated. The fact that patients are involved in the setting of goals makes the approach patient centred. In reality full patient participation is difficult to achieve. Many of the reasons for this are discussed in chapter 3. This approach was used in a multi-centre study (Corner *et al.* 1998) which highlighted the challenges to developing this approach further. The failure to identify agreed goals and then set appropriate guides to action militated against goal attainment scaling as a method of measuring outcome in a study of patients attending day hospitals. Yet, if the criteria delineated by Rockwood (1992) were to be present they would make a more person-centred approach to outcome measurement. Such an approach shares some of the same disadvantages of the approaches to quality of life by Ruta (1994) and O'Boyle and colleagues (1992) in that it is highly labour intensive, requiring skilled interviewers to carry out the procedures and requires further work to establish its psychometric robustness. For example, the measure of whether goals have been achieved is subjective and there is no way of ensuring that goals set are not simplified, hence maximising a person's score.

Approaches to person-centred outcome measures have tended to draw on positivist and interpretative epistemologies and have included structured questionnaires and scales. There are limitations to using such scales to examine such complex phenomena and one has to question whether these are the most appropriate means of understanding patients' perceptions. Brooking (1986) having developed such a scale, albeit for health professionals, argues the need for a more qualitative study to look at responses in more depth. Given that the term 'quality of life' alone means such different things to different people, the attempts to quantify and generalise seems inappropriate and one might question the validity of the tools. Many questionnaires are also concerned with specific



aspects of care, listing tasks and focusing on practical skills and do not take wider community and social context into account. In general research in this area relies on self-report questionnaires and does not explore attitudes and behaviours in reality, failing to explain *why* a person believes x, y or z. Therefore, views given in this type of research might be at worse false statements or at best theoretical guesses rendered meaningless when applied in actual practice. For example, respondents (e.g. health professionals) might claim to include patients in care and express positive attitudes towards the concept, however in the reality they might feel threatened by sharing their expert knowledge or make judgements about the patients ability or need to know, and as a result might actively inhibit participation in practice.

Waterworth and Luker did a small study based on a convenience sample of twelve patients interviews concerning their views on being involved in decisions concerning their own treatment and nursing care. Findings suggest that some patients are more concerned about 'doing what is right', pleasing the staff, than in participating in decisions concerning care (Waterworth and Luker, 1990). This raises some interesting issues which imply that patients may indeed be reluctant collaborators in care because they feel coerced into doing so by professionals. This is at absolute odds with the true notion of lay participation, which would see the decision not to participate as a valid one and that patients are empowered to make decisions which may be different to the one a health professional may have preferred.

## **Summary**

There are clearly problems in taking a positivist approach to research and in using structured instruments to measure complex phenomena. Structured



instruments are unlikely to include all relevant aspects for each individual and it is doubtful if respondents share common understandings to the same issue. The fragmentary nature of this group of studies, reportedly interested in the same concept, but focusing on different aspects make the comparison of findings difficult and as a whole largely inconclusive. Once more they tend to focus on theoretical perceptions rather than deal with issues in reality. There appears to be a suggestion in the literature that perceptions vary with age, in that the younger of the population hold more positive attitudes than the older of the population (Bowling, 1995). Given that much care in the community occurs with older people, and greater participation by this group is currently being advocated, this is a significant finding worthy of further study, and it will be interesting to explore the views of older people further. Differences in social groups also suggest different views being held towards this concept. This emphasises the need to acknowledge that care means different things to different people and cautions against making generalisations among and between groups. Cassileth *et al.* (1980) reported that the setting may influence preferences for information and that patients who seek treatment in large medical centres may differ from those who go elsewhere (for cancer treatment). This again points to the difficulties of using a survey method where it is not possible to explore with participants in more depth the *reasons* for their responses. Whilst it is very difficult to compare findings from the various studies undertaken, it appears there is a link between younger age and greater acceptance of involvement in health care. But one needs to question what motivates different groups to give different opinions and take into account other wider influences such as oppression and ageism.

## Chapter 6

### Design of study and methods of data collection

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the sociological imagination enables its possessor to understand the larger historical scene in terms of its meaning for inner life and external career of a variety of individuals. It enables him to take into account how individuals, in their daily experience, often become falsely conscious of their social positions....The sociological imagination enables us to grasp history and biography and the relations between the two within society  
(Wright-Mills, 1959, pp11-12)

#### Overview

The research methods which have accompanied the recent burgeoning of interest in the science of outcome measurement have largely been based on deductive theorising. Whether qualitative or quantitative, the theoretical stance that has been adopted by researchers has involved aspects of hypothesis testing or measurement and this has tended to focus on a common core of functional areas.

It is this thesis' contention that until some of the conceptual problems surrounding outcome measurement have been resolved, the precise value and meaning of the data using these methods cannot be assessed. The intention is, therefore, to try and understand the experiences of older people from the perspective of the 'older person'; to listen and to understand how people articulate their experiences, needs and desires, and how they conceptualise them. What do they value? What are their views on, and experiences of, health and statutory services? How do they judge what they need? How do they conceptualise outcome?

In this chapter the way the participants were selected is also outlined, along with the principles which guided the interviews, and how the analysis was carried out. In reality, the approach adopted creates overlaps between participant selection, data collection and analysis, but these have been artificially separated to facilitate the reading of the thesis.

It was necessary to search for a method which was relatively unstructured in approach, as the participants were to both define and extend the area of enquiry. Theory often defines method and therefore the choice of method was not just a pragmatic decision, but one securely embedded in the theoretical approach adopted. The explanatory nature of the proposed study and its emphasis on individual's views meant that use of qualitative research methods seemed an appropriate and accessible way of collecting the type of data required in response to the research questions being asked. It was decided to use focus groups as a preliminary study to establish a range of themes and to explore these in greater depth in relatively unstructured focus interviews.

## **Theoretical perspective**

A role of theory is to provide explanations of the connections between what facts already exist about some phenomena (Bond and Bond, 1994). Theory is useful in that it explains past events and in turn should be able to predict future events and generate new theoretical thought. Health services research uses a variety of theoretical perspectives, drawing on theories, for example, from anthropology, economics, psychology and sociology which reflect the multidisciplinary nature of the discipline.



## Symbolic interactionism

The theoretical perspective adopted is symbolic interaction (Denzin, 1974; Denzin, 1978). Symbolic interactionism is a term given to a number of characteristics which identify a broad sociological and psychological perspective. One of the core ideas is that sociologists should proceed to *understand* those they study (Coleman and Bond, 1990).

This is achieved by attempting to look upon the world as they do; by appreciating how the world looks to them. To this is added learning the ideas, motives and goals which make people act. By learning these things about individuals, sociologists should gain an understanding of why they act in a certain way in order to achieve certain ends in the face of their individual circumstances as they see them

(Coleman and Bond, 1990, p93)

The focus is, then on *understanding the individual with reference to their particular social circumstances*. It is fundamentally different from structuralist perspectives which emphasise social structures and facts that exist independently of individual members and society.

Symbolic interactionism was mainly developed by Mead (1964) and the Chicago School of sociologists. Central to this approach is that there is a difference between animal *reaction* and human *conduct*. Conduct requires the possession of *mind* which is distinctive to the human species (Bond and Bond, 1994). To this is added the concept of *self*. Individuals both undergo experiences and are aware of doing so (Bond and Bond, 1994). Mead (1934) distinguishes between human *action* and human *behaviour*. Behaviour is limited to a stimulus-response relationship, whereas the concept of action 'depends on an individual's ability to plan their actions, reflecting on past experience, and to reflect on themselves in the same way as they look on other kinds of objects in the environment' (Bond and Bond, 1994). Language becomes a central concept as it is through this that

we learn to act how others *expect* us to, and the self-consciousness necessary to engage in social life (Coleman and Bond, 1990).

For different individuals, the same object will have very different meanings depending on previous experiences, knowledge and current circumstances (Bond and Bond, 1994). Explaining how individuals interpret the complexity of social interaction is central to symbolic interactionist approaches. Blumer (1969) advocates an approach which seeks to examine details of particular instances of social life as they occur in their particular, natural settings:

In advocating a naturalistic approach symbolic interactionists aim to put themselves in the position of seeing the world in the same way as the people they are studying

(Bond and Bond, 1994)

Mead's original theory of social behaviourism concentrated on sense-data that humans receive. He pointed out that much of the sense-data that we receive are symbolic, requiring decoding and interpretation to establish what is meant. An often used example is that of a school classroom. If a pupil raises his hand, the teacher's observation is sense-data. However, the teacher now has to decide what these data represent or symbolise. Is the pupil volunteering to answer a question, requesting permission to leave the room, relieving a cramp or what? The teacher must then consider whether to acknowledge the behaviour by collecting further information, perhaps by asking the pupil what they want. Having done that, the teacher still has to consider the status of the information. If the pupil wants to go to the toilet, does the pupil really need to do so, or is it an attempt to disrupt the lesson or to manufacture the opportunity to smoke an illicit cigarette or even some combination of these? A process of this kind can not be captured by a set of conditioned reflexes (Murphy *et al.* 1998).



The Chicago studies had a distinctive perspective on medical work and medical organisations which they tended to approach 'from below'. *Boys in White* for example, is often contrasted with the contemporaneous study of medical education by a team from Columbia University, *the Student Physician* (Merton, 1972), which is seen as having a much more establishment perspective. The Kansas students are strategic actors, trying to work out how to survive in a complex organisation that makes unbearable demands on them. The Columbia students are clearly more embryonic doctors, compliant absorbers of the values and culture of their profession (Atkinson, 1983). The same spirit was carried into studies of patients - Goffman's *Asylums* (1961) and Davis's *Passage Through Crisis* (1963), which studied families where a child had polio. Patients struggle to make sense of the organisations and the professional actors who confront them. In the mental hospital, the inmates create an underworld of their own where they show a remarkable degree of initiative and creativity in managing the strange and impoverished environment that surrounds them. In the TB ward, patients construct their own benchmarks of progress from one day to another. Are they getting better or worse? When will they be allowed out? Allowed home? They observe the hygiene rituals of staff. Why do some professionals wear masks and others not, when performing exactly the same task? The polio victims and their families have the same problem of judging recovery. How much progress have they made? How much will they make? The genuine clinical uncertainties of prognosis are compounded by the functional uncertainties engendered by the professionals, the theory that compliance with treatment can be better encouraged by keeping families hopeful, by stressing the unknowns beyond the point when the doctors are quite certain of a likely outcome. These studies retain an important contemporary relevance because of the way in which they deal with fundamental questions about the social organisation of health care which tend to



recur in new forms whenever new technologies arise. The distinction between functional and clinical uncertainty, for example, recurs in recent studies of genetic counselling (Bosk, 1992).

Criticisms levelled at symbolic interactionism include an indifference to the problems of evidence, proof and systematic theory; an avoidance of regard for structural constraints which foreclose available choices open to individuals; and an absence of any attempt to gain an overview of social organisation, with a neglect of the various sources of social stratification (Bond and Bond, 1986).

Bond and Bond (1986) point out that much of this criticism is not only directed at the theoretical basis of symbolic interactionism but also at the research methods which it employs. Qualitative methods with the emphasis on the lived experience is at odds with quantitative methods, usually employed by those from a structuralist perspective. However, Bond and Bond (1994) stress that symbolic interactionism provides innumerable insights into our understanding of health and illness, and a number of original ideas from symbolic interactionists have been absorbed into mainstream sociological thought.

## **Choice of methods**

### **Critique of positivism and quantitative techniques**

Positivism, broadly defined, relates to the generation of theory and the collection and analysis of data, while the method of basing general statements on accumulated observations of specific instances is known as induction. The use of the word, however, is ambiguous, and it is misleading to describe all research within the quantitative tradition as positivist and all within the qualitative tradition as anti-positivist. Positivism in philosophy revolves around the contention, or implicit assumption, that the notions and statements of science constitute a framework by which the nature of any form of knowledge may be determined

(Comte, 1830). Positivism in sociology may be broadly represented as depending upon the assertion that the concepts and methods employed in the natural sciences can be applied to a form of 'man' or a natural science of society (Giddens, 1974).

Scientific rationality assumes there is one true reality which can be discovered if only researchers are objective enough. Objectivity is paramount if the spectre of bias is to be kept at bay. This pursuit of objectivity has, in part, been influenced by the need of social scientists to attain the status accorded to those working in the natural sciences (Giddens, 1976). This need for scientific validation has resulted in largely uncritical adoption of the rules of the natural sciences. Hence social behaviour and events are treated as though they have an objective and constraining reality. This view of reality is perhaps most stringently fundamentally opposed by feminists, along with the objective/subjective dichotomy. Rich (1979), for example, in refuting the notion of objectivity suggests that, as an essentially male concern, objectivity is no more than the term for male subjectivity.

The interviewee who provides 'inconsistent' or 'inaccurate' responses, which may emerge within the data-collection process or in a conversation with the respondent after the interview, creates problems for the analysis of the data. Analysis is often based on the assumption that there is a consistent, contradiction-free reality which each respondent adheres to. Respondents who do not conform to the passive co-operative role ascribed to them are either labelled deviant and their views reinterpreted, or ignored altogether. Non-response, or the refusal to provide any or certain items of information, appear either as a statistic or in an appendix to the results. They are only really explored when a large number of people do not respond in the required way.



Many of the methods in health services research, for example survey methods, are positivist in their approach and certainly approaches to outcome measurement have been dominated by this paradigm. Approaches to measuring outcomes of care tend to be positivist in nature and generally use structured measurement scales. The validity of using such scales is open to question. The themes that are being discussed are complex phenomena. Structured instruments are unlikely to include all the relevant aspects for each individual and it is doubtful that respondents share common understandings when responding to the same issues. In this way structured instruments are unlikely to accurately measure perceptions of health care. Whilst other more interpretative studies tend to examine concepts in detail, they still deal with the topic at a theoretical level and so the application of findings to practice is doubtful.

## **Qualitative techniques**

The debate surrounding the methodological rigour of qualitative research is confounded by its diversity and lack of consensus about the rules to which it ought to conform and whether it is comparable to quantitative research.

Qualitative techniques are not new, although they have only relatively recently been introduced in to the arena of health technology assessment. Murphy et al (1998) stress the importance of high quality qualitative research and the significant contribution its methods can make to health services research:

Although these often frustrate practical men and women who would like to see all research findings reduced to checklists, bullet points or score cards for action, they are fundamental to understanding the limits of confidence to our ability to have knowledge of and to act upon the world around us. A distinctive feature of qualitative research has been its willingness to accept and to confront these problems, even at the cost of underselling the robustness of its own claim to representativeness, reliability and validity

(Murphy et al. 1998, p55)



By the selection of a qualitative design for this study, it was hoped to get behind the participants' formal public statements and uncover their personal perceptions (Mays and Pope, 1996). Unlike quantitative research, which seeks to enumerate, qualitative research aims to answer questions such as "what, why and how" (Pope and Mays, 1993). Qualitative methods attempt, by conducting the research in natural rather than experimental settings, to present the world and perspectives on that world, in terms of the concepts, behaviours, perceptions and accounts of the people being investigated (Marshall and Rossman, 1995).

The main criticisms of qualitative research are that: it is an assembly of anecdotes which are subject to researcher bias; it lacks reproducibility; and finally it is criticised for lacking generalisability. However, Mays and Pope (1996) argue that, providing researchers attend to issues of validity, reliability and generalisability, then the integrity of qualitative research can be protected. As in quantitative research, the aim is to ensure rigour in systematic research design, data collection, interpretation and communication (Morse, 1991). Qualitative research should produce a coherent, plausible explanation of the phenomenon under scrutiny and provide an independent account of the methodology used, thus enabling another researcher to analyse the same data in the same way and to arrive at similar conclusions.

In order to uncover respondents' personal perceptions, a number of authors (Mays and Pope, 1996e; Scambler and Hopkins, 1988; Whyte, 1980; Marshall and Rossman, 1995) stress the importance of not imposing a priori categories and concepts from the researcher's own professional knowledge onto the process of data collection. Instead of beginning with a hypothesis that precedes data collection, they recommend that the researcher goes backwards and forwards between the raw data and the conceptualisation process. In this way, it is possible to make sense of the data throughout the data collection. This

iterative process enables early stages of the research to inform subsequent stages (Pope and Mays, 1995). If findings diverge from those predicted by a theory, they can lead to a revision of the theory. This way, theoretical developments are grounded in the data.

## The use of grounded theory

a grounded theory is one that is inductively derived from the study of the phenomena it represents

(Strauss and Corbin, 1990, p23)

Grounded theory provides a set of useful research strategies for studying the experience of chronic illness (Charmaz, 1990). It was developed by Glaser and Strauss (1967) and refined by Strauss et al (1984). According to Glaser and Strauss (1967) grounded theory is not a philosophy of behaviour, nor a specific method or technique, but a *style* of doing research. This is felt to be appropriate here: grounded theory is thought to be a set of approaches generating and advancing theory, rather than a specific, single technique. Its origins were in symbolic interactionism, and it stands at the meeting point of two strands of sociological thought; the American pragmatists (for example, Dewey and Mead) and the Chicago school (for example, Blumer). The contributions that these schools of thought made to the development of grounded theory have been identified by Strauss and Corbin (1990, pp24-25) as:

- the need to get out into the field;
- the importance of theory grounded in reality to the development of a discipline;
- the nature of experiences as continually evolving;
- the active role of persons in shaping the worlds in which they live;
- the variability and complexity of life, and an emphasis on change and process;



- the presence of inter-relationships among conditions, meanings and actions.

It is an approach, then, which can specifically address issues of identities, social processes and shared experiences. Blumer (1969) when discussing the philosophy behind grounded theory, comments:

human beings act towards things on the basis of *meaning* that things have for them. The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows, and these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters

(Blumer, 1969,p2)

In developing grounded theory, Glaser and Strauss (1978) were attempting to bring the researcher close to the issues that people experience, and develop a rigorous, qualitative methodology with its own integrity, distinct from quantitative methods. The emphasis in grounded theory is on deriving theories and explanations of social structures and processes *inductively*, by grounding explanations for observed phenomena or events firmly in the data that have been collected and uncovering, in Conrad's words 'the insider's perspective' (Conrad, 1990).

A number of authors (Strauss and Corbin, 1990; Conrad, 1987), (Corbin and Strauss, 1987; Bury, 1991) stress the importance of *listening* to the patient's point of view in chronic illness. Conrad (1987) differentiates between the 'insiders' (i.e. the patient's) and the 'outsiders' (i.e. the health professional's) view of chronic illness, and argues that to understand the chronic condition, health care professionals must see things from the patient's own point of view. This insider view of illness considers how people first recognise early symptoms, how they react to the diagnosis and how they cope with the illness course (Conrad, 1987). Conrad (1987) recommends that the sociology of illness experience needs to be based on systematically collected and analysed data from a sufficient number and variety of people with an illness. This perspective needs to



focus on the *meaning* of illness, the social organisation of the sufferer's world and the strategies used in adaptation. Important considerations include:

what kind of theories and explanations they develop to make sense of these unusual events; what they do about their problems, and how they come to seek medical care and with what concerns and explanations; what impact diagnosis had on them, and how they cope with a medical label and managing regimes. It must examine the relationship with family members, friends and work associates. It must consider how people contend with formal and informal disenfranchisements based on a diagnosis, how people adapt to physical discomfort, what it is like to make routine visits for medical care, how medical personnel appear to patients and what strategies people use simply to 'get by' in their lives

(Conrad, 1987, p5)

The thrust of the grounded theory method, 'is toward the development of theory without any particular commitment to specific kinds of data, lines of research or theoretical interests' (Strauss, 1987). The goal of grounded theory is to generate theory, by allowing it to emerge from the data rather than from some prior conceptualisation.

Despite the many suspicions of grounded theory as a method (Stanley and Wise, 1983,p152), the principles of grounded theory as a broad framework for some elements of this study seemed useful in that it offered the opportunity to develop an analytical approach which was grounded in the experiences and meaning of the people interviewed. Strauss (1987) stated that it was possible to retain the spirit of grounded theory without rigidly following the original method:

we take the stand about our suggested methods that they are by no means to be regarded as hard and fixed rules for converting data into effective theory. They constitute guidelines that should help most researchers in their enterprises....these are to be thought of as operational aids...modify them in accordance with your own research

(Strauss, 1987, p7)

Glaser and Strauss challenged the dominance of quantitative analysis methods and disagreed with the practice of researchers being more concerned with

hypothesis testing, and subsequently trying to force their data into predefined categories. They implied that as researchers, they were afraid to follow up unexpected emerging ideas for fear of undermining the rigour of their work. Grounded theory, the authors suggested, would facilitate rigour amongst sociologists in that it can help sociologists to interpret what is found.

Glaser and Strauss (1967) identified two levels of theory construction achievable using grounded theory: formal and substantive theory. Formal theory is that developed for a formal or conceptual area of enquiry, such as stigma, deviant behaviour or socialisation. Substantive theory relates to that developed for a substantive or empirical area of sociological enquiry, for example, patient care. Both of these types of theory are considered to be middle-range theory, falling between 'minor working hypotheses of everyday life' and 'all inclusive grand theories' (Glaser and Strauss, 1967, p33).

The distinctive features of grounded theory include theoretical sampling and certain methodological guidelines such as making constant comparisons, and the use of a coding paradigm to ensure conceptual development and density.

### **Theoretical sampling**

Theoretical sampling is a type of non-probability sampling in which the objective of developing theory or explanation guides the process of sampling and data collection. Unlike random statistical sampling, which is used as the basis for obtaining evidence on the distribution of people among categories, the purpose of theoretical sampling is to discover categories and their properties and to define their relationship to each other. Theoretical sampling is about incidents rather than people *per se*.

Respondents are not, as in most quantitative methods of sampling, selected definitively in advance of data collection. Quantitative enquiry is intended to identify trends, explore correlations and causation, to indicate frequency and make statistical inferences . This is achieved by using random or probability samples, large samples to minimise sample error and increase confidence; i.e. looking for statistical representation. With theoretical sampling 'the analyst decides on analytical grounds what data to collect next and where to find them' (Strauss, 1978) and the sample emerges as data collection, coding and analysis proceed. Glaser and Strauss (1987) advise the researcher to select participants, collect codes and analyse preliminary data to produce a preliminary theoretical explanation before deciding which further data to select. Once these data are analysed, refinements are made to theory, which in turn will guide further sampling and data collection. Therefore, the relation between sampling and explanation is theoretically led (Mays and Pope, 1996).

Sampling and sample size is linked to the nature of the research question. In order to provide information which can generate, illuminate and explain issues around the research question, the cases must be relevant to the question. The cases must form a coherent picture from which reliable generalisations and robust explanations can be created. This minimises possible bias arising from selecting a sample on the basis of convenience.

Theoretical sampling serves many purposes within a grounded theory approach. It enables data to be collected from groups, or sub-groups, of the population being studied in order to supplement, clarify and/or validate the stage of analysis reached. It also enables anomalies and contradictions in the coding schemes to be resolved.



The procedure for this method of sampling differs according to the level of generality at which the theorising is to occur and with the stage that the analysis is at. In the case of formal theory, where the focus is on a high level of generality, it is expected that the sampling will occur in different substantive areas. The level of sampling and data collection required to achieve the generation of formal theory was beyond the scope of this study, primarily because of resource and time constraints. Had a formal theory of outcome measurement been the aim of the study, theoretical sampling would have included interviewing other population groups, with different types of condition, in different settings and contexts, and with different professionals working in the various settings. This would have taken time in terms of locating and negotiating access to different groups of people.

Suitable qualitative techniques were explored to collect the data.

## **Focus Groups**

### **What are focus groups?**

The technique of focus groups originated from marketing (Kitzinger, 1996), but they are now increasingly used in academic research and health care settings (Morgan, 1993). Focus groups consist of a group of people brought together to discuss issues which are felt to be important to the research (Kitzinger, 1996).

Focus groups have been described in a number of ways:

- a small, relatively homogenous group that meets with a trained moderator who facilitates a 90 to 120 minute discussion in a non-threatening, relaxed environment about a selected topic (Bers, 1989)
- a technique involving the use of in-depth interviews in which the participants are selected because they are a purposive, although not necessarily

representative, sample of a specific population, these groups being 'focused on a given topic' (Lederman, 1990)

- a tool for collecting information in which a number of respondents simultaneously discuss a given topic under the guidance of a moderator (Thomas *et al.* 1995).

### **Focus group rational**

Focus groups are a cost-effective means of gathering data from a cross-section of individuals and are also quicker than individual interviews (Thomas *et al.* 1995). They are particularly useful in understanding the issues surrounding a topic, and in exploring participants' expressed beliefs, attitudes and values. The specific technique is to use group interaction (Morgan, 1988) and they are useful for generating data on 'how' and 'why' people act or feel the way they do. So, although the data are not necessarily representative, focus groups are an excellent way to explore issues and quickly establish a wide range of views, experiences and concepts (Lederman, 1990).

Kingry *et al* (1990) identified several uses for focus groups: in generating constructs, hypotheses, and information for questionnaire development; as an aid to product development (e.g. in marketing or educational programmes) or to interpret results from quantitative studies (Bellenger *et al.* 1976). Some researchers claim that the interactive nature of focus group discussions provides different information to that collected from individual interviews. For example, Goldman (1990) postulates 'By virtue of the interaction and common relevant interests of its members, the group offers more and qualitatively different information than can be obtained from the sum of its individual human parts'. Similarly, Kingrey *et al* (1990) claim 'the synergy of the group has the potential to uncover important constructs which may be lost with individually generated data'.

Lederman (1990) argues that data generated in focus group interviews are often richer and deeper than data elicited in the one to one interview situation, although Thomas et al (1995) found no evidence to support this finding.

Basch (1987) argues that focus groups emphasise the interaction between respondents, they may create a more relaxed climate and a greater serendipity of response. This is in contrast to the potentially limited interaction between interviewer and respondent in individual interviews. As Lederman (1990) notes, it is the group, rather than the individual that is interviewed. Caplan (1994) states also that focus groups offer a unique synergy and spontaneity through participant interaction that can quickly generate valuable ideas. This is seen as a powerful element not found in other techniques, such as survey questionnaires and one-to-one interviewing, which obtain individual responses only (Caplan, 1990).

Group pressures may inhibit participants from giving misleading information (Basch, 1987) and may create an atmosphere where sensitive topics may be discussed openly, although this may depend on the topic under consideration. It has also been suggested that peer group effects provoke greater candour and provide a more emotionally-charged climate than individual interviews (Goldman, 1962). The moderator can probe group members' reactions to each other's opinions and experiences (Basch, 1987). There may also be different resource implications of focus groups compared with individual interviews, with some researchers claiming that focus groups may be more time or cost-effective, and others seeing little advantage in either method (Bers, 1989).

### **Focus group process**

The focus group interview usually comprises between 3 - 12 participants, although recommendations vary, drawn from a sample according to the research topic under investigation.



### ***The role of the facilitator***

The role of the moderator or facilitator in promoting group interaction is important (Fern, 1982). This role includes maximising interaction between participants (Reiskin, 1992; Kitzinger, 1994), focusing the discussion on the relevant subject matter in a non-directive manner (Mendes de Almeida, 1980) and providing assistance in 'mining' participants information (Lederman, 1990). Group facilitators are ideally skilled and are equipped with a knowledge of group processes and discussion techniques (Lederman, 1990), for example, in order to suppress dominant respondents and encourage passive group members to participate (Tynan and Drayton, 1988). Moderators can also employ group exercises: in Kitzinger's (1994) study, for example, participants were asked to sort piles of cards representing the degree of 'risk' of AIDS according to 'type of person'.

(Fern, 1982) tested the hypothesis that the skill of the moderator in managing group processes may affect the richness of the data generated, using focus groups with no moderator as a comparison. Groups led by moderators did not produce significantly more ideas than unmediated groups. Interestingly, however, participants from the moderated group were more enthusiastic and found the task more exciting and enjoyable (Thomas *et al.* 1995).

Both focus group discussions and focus interviews are guided by a moderator or interviewer who uses a topic guide (see later section).

### **Limitations of focus groups**

Some researchers argue, that due to the invariably small and often unrepresentative samples used in focus groups, findings cannot be extrapolated to larger populations (Bers, 1989; Mendes de Almeida, 1980). Even if a systematic approach to sample selection was taken, some participants may

dominate the discussion with others not sharing their views, thus findings would remain ungeneralisable (Basch, 1987).

The technique has been criticised for its unreliability: it is said to lend itself more easily to supporting preconceptions of the researcher because of its reliance on moderation (Basch, 1987). Furthermore, findings cannot be replicated (Mendes de Almeida, 1980) and may have varied with different participants, a different moderator or in a different setting (Calder, 1977). Bias could also be introduced by differing levels of 'talkativeness' amongst group members (Kitzinger, 1994; Drayton *et al.* 1989) and by other participant behaviour such as 'social posturing': trying to please the moderator and not wanting to appear 'anything less than bright, witty and charming' (Seymour, 1987). Acquiescence bias, however, could also occur in individual interviews. Group behaviour could result in 'forced compliance', where participants state agreement with the viewpoint of other, more forceful individuals even if this is not their actual view (Seymour, 1987).

The technique can only be used with groups who can verbalise their opinions, thus certain groups of potentially valuable contributors, for example those with hearing or speech problems, are excluded (Richter *et al.* 1991), (Basch, 1987). This criticism can also, of course, be levelled at individual interviews.

While Bers (1989) states that focus group research is based upon well-developed principles of sociology, psychology and communication, she also notes that 'focus group research as the subject of studies about methodologies is less visible' (Bers, 1989). Similarly, Fern (1982) argues that little is known about the methodological aspects of this approach compared with other data collection techniques (e.g. individual interviewing). Bertrand *et al* (1994) point to the lack of practical information on how to systematically analyse focus group data. Bers



(1989) suggests analysis requires a 'systematic and verifiable process' which should enable other researchers following the process to reach the same conclusions. Several approaches were found in the literature, ranging from examining transcripts for trends and patterns (Bers, 1989) and summary statements capturing the essence of the data (Lederman, 1990) to more structured approaches, for example coding data into pre-determined categories (Lederman, 1990) and content analysis (Morgan, 1988; Reiskin, 1992).

Specific issues in the analysis of focus groups are the ability to identify individual participants in taped transcripts (Watts and Ebbutt, 1987) although this is considered by some not to be necessary (Folch-Lyon and Trost, 1981), and establishing the typicality of quoted material (Tynan and Drayton, 1988). Kitzinger (1994) notes that while so much emphasis is placed on the uniqueness of interaction, little attention has been given to the conversation between participants in analysing transcripts. While Kitzinger uses interactions between participants to illustrate her arguments, she gives little practical guidance on how to conduct such an analysis. A further fundamental issue is how to analyse 'shifts' in group opinions throughout the discussion (Drayton *et al.* 1989); there appear to be no suggestions as to how this could be done.

### *Existing groups*

There are disadvantages to using an existing group for a focus group; Bringing together a group who already know each other could hinder the group dynamics and the process might be influenced by existing relationships or hierarchies within the group. This might introduce bias and skew the discussion; for example, acknowledged 'strong personalities' might make their points more forcibly, at the expense of the opinion of less forceful members. However, Kitzinger (1994) following work with AIDS patients, suggests that previous relationships between group members might in fact help the group process, as



members may feel more comfortable and may offer mutual support or back each other up when recounting an incident. A further advantage of using an existing group is that the groups can be organised relatively quickly and potential problems, such as transport arrangements, do not arise.

## **Focus Interviews**

Focus interviews were used in this study to elicit individual's views. This is a data collection method used extensively by qualitative researchers, and has been described by Kahn and Cannell (1957) as a 'conversation with a purpose'.

Typically, the researcher explores a few general topics to help uncover the participant's perspective but otherwise respects how the participant structures the response. According to Marshall and Rossman (1995):

the participant's perspective on the phenomenon of interest should unfold as the participant views it, not as the researcher views it...The most important aspects of the interviewer's approach concerns conveying an attitude of acceptance that the participant's information is valuable and useful

(Marshall and Rossman, 1995, p80)

Like all data collection methods, focus interviews have particular strengths and weaknesses. As interviews involve personal interaction, co-operation is essential and the participant may be uncomfortable sharing all that the interviewer hopes to explore, or may have good reason not to be truthful (Douglas, 1976). The interviewer must have the necessary skills in listening, framing questions, interaction and gentle probing for elaboration (Marshall and Rossman, 1995) and be trained in interviewing techniques to ask the appropriate questions to elicit long narratives from participants (Bryman, 1988). The data, like most qualitative methods, are also time-consuming to analyse (Patton, 1990).

However, an interview is a valuable way to gather large amounts of data quickly (Marshall and Rossman, 1995). Immediate follow-up and clarification are

possible, enabling the researcher to understand the meaning people hold for their everyday activities. The additional benefits for focus interviews are that they are interactive, responsive to language and concepts used by the respondent and permit deeper investigation of participant relevant topics which are uncovered during the course of the interview.

In this study, focus interviews were chosen as a method to follow through themes generated in the focus group study and to try and provide a forum where a deeper and detailed understanding of the issues could be achieved.

## **Study population**

### **Access to study site**

Qualitative samples are not arbitrary collections of participants. Theoretical sampling is a controlled procedure concerned with selecting participants *on purpose* who will be able to provide data to address the research issues. The dimensions or factors according to which the sample is drawn up are theoretically and analytically linked to the research questions being asked and these factors are used to set quotas and to define the boundaries of the sample (Social and Community Planning Research (SCPR)). The aim of setting quotas is to ensure the range, relevance and diversity of the sample to meet information needs; it is not, as discussed previously, to provide a representative sample. Quota controls provide a means of monitoring that the sample selection is focused on the information required to address the research questions. The SCPR give guidelines for setting quotas which include:

- be realistic and practical
- do not make the design too complex
- do not set too many quotas

- do not be over prescriptive, but be flexible
- is the quota accessible? Can you monitor the selection process?
- be prepared to give explanations if quotas have not been achieved

### *Day hospitals*

Given, the level of theory generation anticipated as feasible within the study constraints, and that the research aim was to explore outcomes of older people in *rehabilitation settings*, there seemed distinct advantages to be gained from using existing rehabilitation services as a basis to select participants for the study.

Day hospitals are only one example of rehabilitation services. Almost all health authorities purchase services from at least one day hospital. They provide a multidisciplinary service for a heterogeneous group of people, based largely upon the objectives of functional assessment, rehabilitation, physical maintenance, the delivery of medical and nursing procedures and often, respite and social care. Wide national and local variation exists in the range of services that are provided, but they tend to operate as an extended out-patient department, where patients may attend for an average of six weeks, for a variety of interventions for acute and chronic illnesses and come into contact with a variety of health professionals (Royal College of Physicians and the British Geriatrics Society, 1994). The majority of patients attending a day hospital live in the community and are referred either from the main hospital wards following an in-patient stay or directly from the community. Day hospitals form a bridge between primary and secondary care, and between health and social services.

The decision to base the study in a particular area was a pragmatic one, based on the fact that there was already a considerable amount of older age research taking place in one area of the region, and therefore there was a perceived



danger of 'respondent/participant overload'. As an alternative, the chosen study area was easily accessible and had an added advantage of having an established working relationship with members of the multidisciplinary team at the hospital to facilitate access.

### ***Permission to work in the day hospital***

Meetings were arranged with the day hospital manager and the director of elderly care services at the hospital to discuss the outline proposal. The purpose of the study was explained, along with why this particular area had been selected as a study centre and why access to the day hospital was desirable. Both were keen to participate in the study and a temporary contract to work at the hospital was arranged.

Meetings were subsequently arranged with the day hospital staff to explain the study to them. This was to try and reassure them that this work was in no way connected with the day hospital and that there would be no interference with their daily routine. The fact that access would be needed to patient notes was explained, along with the fact that short interviews with people attending the day hospital would be taking place. The staff were enthusiastic and very supportive of the study throughout and regular feedback to the day hospital team during the study was given.

## **Recruiting participants**

The specific methods of recruitment for the focus groups and the focus interviews are explained in detail in the relevant sections.

## **Focus interviews**

In the very early stages of the project, when considering which group of people to interview, a specific group of patients, for example, those who had suffered a

stroke, was considered. However, this idea was rejected as an assumption of the study was that older people are not a homogenous group of people. An objective was to take a fresh approach to outcome, and existing approaches focus on diagnosis as a primary factor, and group people together under diagnostic labels, such as stroke, diabetics, heart failure. This was felt to be more in tune with the medical model. The intended approach was to attempt to uncover additional factors which may impinge on how people consider outcome in a wider context. Therefore, it was important not to limit the focus by using disease categories to actually select participants. The impact of specific conditions, however, was an important area to explore with participants. The purpose of the focus interviews was to try and unravel how people conceptualised outcome, how they organised their beliefs, values and experiences, how they found meaning, from these experiences, without imposing the stereotypical ideas inherent in labels of diagnosis and age. It was possible that the nature of disease and the stage of the disease would be influential in determining how people considered outcome, but this was included in the topic list and would emerge anyway.

Older people have been noted as being more likely to conform to traditional models of care (Cassileth *et al.* 1980) than other groups in the population. However, in these studies the definition of 'old' appears to be 'over 60', i.e. on chronological age alone, and so does not take account of any differences within this group. There may, or may not, be age differences in how people conceptualise their health care and outcome and so it was decided that chronological age would form part of the initial participant selection. Similarly, a criticism of many outcome measures is that they are gender specific, and so in attempting to address user-centredness there may be gender differences which are important in what people choose to identify. Participants were also selected

on the basis of gender. Socio-economic status is well documented as affecting health (Townsend *et al.* 1992) and so this was also on the initial sampling criteria. This would hopefully give a diverse group of people on which to base the initial interview process. Ethnicity was considered. However, the area is ethnically homogenous and only the majority culture participated. New themes and theories were incorporated as they emerged in subsequent interviews.

### ***Screening questionnaire***

There are general questions about the ethics and general feasibility of theoretical sampling. For studies which need to sample on the basis of obscure characteristics, the process of theoretical sampling may involve a fairly detailed preliminary interview. The screening questionnaire has a specific purpose of determining a participant's eligibility in the study. It can also be helpful in providing additional background information, and for encouraging participation. Ideally, these are short (5 minutes) and include an explanation of the purpose of the research along with assurances of confidentiality and quota checks. If the respondent does not fulfil the required characteristics, the interview is brought to a close. If the participant is suitable for a further interview and agrees to take part in the study, a time and venue for the next interview is arranged. Unless great care is taken, this type of research relationship may leave some respondents powerless with a sense of having their experiences invalidated.

### **Ethical approval and informed consent**

Ethical approval was sought and gained from the local ethics committee, once a preliminary study design had been agreed. This was initially refused, due to questions as to why the day hospital had been selected to recruit patients to the study (even though this was explained). They also stated concerns over the content of the information given to patients. The patient information sheet was



subsequently revised to take account of the comments of the committee, and ethical approval was granted. This process was frustrating, however, and delayed the start of the field work by several months. It also raised important questions about the politics of ethical committees and the challenge they present for non-positivist science. Whether this is a widely held experience for researchers in this area perhaps warrants further investigation.

### ***Participant Information sheets***

The information sheet included information on why participants were being asked to participate; what they were being recruited for; what the interview would involve; how the author got their name and details; and what will happen to the research. Participants were also assured of confidentiality. This is shown in Appendix 1.

### **The topic guide**

The topic guide is a list of topics rather than specific or structured questions. It is used by the moderator or facilitator as a memory aid to help guide the discussion and includes essential subject areas for coverage and specific items which may be useful and relevant to the discussion. The topic guide helps maintain consistency as far as possible across all the interviews (and interviewers, if appropriate) and assists towards a good interview technique, especially with interviewing strategies, language and some phrasing (SCPR). However, to use a topic guide effectively the interviewer obviously needs to be steeped in the background/hypotheses/objectives and purpose of the research as the topic guide is not fixed and is likely to be amended after several interviews to include new concepts or topics that may arise. Also, the order of topics discussed may differ between respondents and groups and as the importance of listening to what participants were saying, listening to their ideas and interpreting and

accepting their 'meaning' is central to the process, the topic guide must be seen as a flexible and dynamic tool.

The focus group study is discussed in the next chapter, along with further details of the study design.

# Chapter 7

## The focus group study

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### Focus group process

The focus groups formed a preliminary stage to develop ideas and research hypotheses. They were intended to provide participant's with an opportunity to express their opinions and thoughts on topics without imposing existing values and approaches on them. The focus groups also provided a forum where people's perceptions about their needs and aspirations could be explored, using their own terms of reference. Their views about aspects of their health and health care could be discussed. The objectives of the focus group study are summarised in table 9.

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**Table 9 Objectives of focus groups**

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- to develop an appropriate vocabulary for discussing outcomes with older people
- to explore what older people understand by the term 'outcome'
- to identify important concepts and domains
- to explore attitudes to participation in health care and barriers to participation
- to explore attitudes to decision making
- to explore the relationship between patient expectation, perceived control and patient outcomes and satisfaction



The main objective of this preliminary study was to develop a research vocabulary to help clarify what language, and which terminology and phrases people understand and relate to so that these could then be used with some confidence in the subsequent focus interviews. This process would also hopefully begin to identify which approaches and methods for discussing outcomes work well, and which work less well, in ways that made sense to older people and their carers. Research questions at this stage included: what do participants understand by the term 'outcome'? What do older people perceive they require to meet their needs? How do older people evaluate their needs and 'what they get'?

Alongside this it was also necessary to identify important concepts and domains which are meaningful to older people as they may be different to those identified by health professionals. Finally, participant's opinions and feelings regarding participation in the planning and progress of their own care, or that of the person that they care for, were sought along with information about barriers to participation in care, and attitudes to decision-making.

## **Recruitment**

It was important that as wide a range of views, attitudes and experiences were gathered at this stage. It was initially hypothesised that age and gender differences may be significant and so it was necessary to include a range of ages and a mix of men and women. Also, some people who had experienced ill-health and ideally some of who had recent experience of receiving rehabilitation services, either as a patient or as a carer were required. Participants who were currently attending the day hospital were therefore contacted, as by the very nature that they were attending, they were currently receiving treatment for a chronic condition in a rehabilitation setting. This group might, therefore, generate

different concepts to a community group of people who were not necessarily currently receiving any treatment or rehabilitation.

Various voluntary organisations around the study area were contacted, and through a 'snowballing' strategy, a list of people to approach was generated. This list was limited and consisted mainly of users of a local day centre and a carer support group. Contact was made with the managers or co-ordinators of these different organisations who were in principle happy for individuals attending these groups to be approached.

It was felt that for a group discussion it would be important for people to have no communication difficulties. This, however, is a limitation of focus groups and disempowers people thought by researchers not to be 'competent'.

A visit was then made to each organisation to talk with the people attending and ask if they would participate. The purpose and format of the focus group was explained, and to explain what their role and contribution would be. Once 'informed' consent to participate in the groups had been gained, participants were sent a letter to their home address, confirming the date, start time, venue, estimated duration and purpose of the focus groups. This was sent within 5 days of the initial discussion. A study information sheet was also enclosed (appendix 1) which gave a contact name and telephone number so people could get in touch if they had any queries, or difficulty in attending. Participants were telephoned on the day before the focus group discussion was due to take place in order to try and maximise attendance. No incentive payments were made, or travel expenses paid.

### ***Finding a suitable venue***

The venue had to be suitable for 8-10 people, and be available during the day, as from past experience with this particular group of people, an evening group

would not be a good idea as some participants may be reluctant to attend at night. It also needed to have full disabled access, facilities such as toilets and tea making facilities and preferably be on a public transport route. Being in close proximity to participant's homes would also be an advantage. Several venues fitted these criteria - two local primary school halls were available during the half term week, and two church halls were also available. The church hall seemed suitable - it was central to the geographical catchment area of the day hospital and fitted all the above criteria.

There is evidence in the literature that patients respond differently if they are in the setting where they are receiving treatment. Therefore, it had been intended that a neutral venue would be used. However, in practice this proved difficult. The people attending the local day centre and carer group specifically asked if they could attend the focus group on the same day as they would normally meet and in the same place. Their reasons included that this would be convenient in terms of transport arrangements, and, in the case of carers, they had already arranged for someone to relieve them while they were out.

Similarly, the day hospital was not an ideal location to hold the focus groups. Limited space was available and patients would have to attend the focus groups on a day that they were not scheduled for treatment, to avoid both interruption to the discussion and further disruptions to day hospital staff and routine. However, few patients attending the day hospital had access to their own transport. A few did have access to a car, but would have to rely on an other person to drive, and most were reliant on public transport. In reality this actually meant they only travelled by ambulance, usually to pick them up and bring them to the day hospital. The practical considerations of holding a focus group outside the day hospital setting for this frailer group of people were therefore considerable.



A pragmatic decision had to be made as to where to hold the focus group discussions. The potential bias that holding the focus groups where participants were used to other activities might introduce to the discussions had to be balanced against the practical barriers of holding the discussions elsewhere and the benefits of maximising participation. Given the practical difficulties involved and the complexity of making alternative arrangements given time and resource constraints, it was decided to hold the focus groups in the day hospital, and at the other organisation's usual meeting places.

## **Designing the topic guide**

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### **Key factors to consider when developing the topic guide**

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#### *The research objective*

- background - reasons for undertaking research
- the central issue
- questions to be answered

#### *The population under study*

- key characteristics
  - extent of variation
- 

### ***Identifying topics***

The content was driven by the research objectives. The design of the topic guide followed a structured process, and involved trying to break down the research objectives into surrounding areas for discussion in such a way as to minimise any preconceptions or assumptions, and to enable the topics to be approached, as far as possible, by participants own manner and words. This would usually be one of the steps to designing any topic guide, but was particularly important in

this case as developing a research vocabulary was one of the original research objectives.

The first part of this process involved 'brainstorming' - thinking about the issues that would need to be covered, including the research objectives and the sample. Several themes and ideas had emerged from the review of the literature including outcome measures, patient participation, consumer choice and decision-making and this informed the 'brainstorm'. Using existing information was an important first stage in developing potential topics to include in the guide, along with drawing on personal and colleague's experience of talking and working with older people.

### ***Ordering topics***

All the ideas from the brainstorm were then listed - this included topics, points to explore, thoughts, hunches etc. - basically everything which might be important. These were then grouped to try and distinguish the various components and sub-groups of a more general issue.

The subsequent topics which emerged were then listed, trying to somehow 'order' topics so that possibly more sensitive or difficult topics appeared later on, and there was a logical order or chronology to the topics which would help the discussion to flow. Hopefully, a carefully planned order might encourage topics to arise spontaneously as far as possible, largely unprompted by the facilitator.

The final stage of the topic guide development, included organising each section of topics into a useable checklist to ensure that each area was covered, and appropriately emphasised, and that it would be easy to use. It was necessary to keep the topic guide as concise as possible, and to learn it, to facilitate being more free to listen and respond to the discussion and think quickly without referring to notes.

The process then moved on to thinking of an initial approach. For example, some time was spent standardising the introduction to help introduce what was potentially a difficult session - many people would be unfamiliar to such a setting, and to discussing such issues, so it was important to try and maximise interest and commitment from the start, but without influencing the content and biasing the discussion. Exactly which people would be recruited to get a range of ideas and answers at this stage was considered.

It was also necessary to consider a way to 'warm-up' the session, starting perhaps with a general and unemotive discussion, but something that may provide useful background and context to the following discussion.

From previous experience, it was apparent to the author, that the language and terms used by health professionals and researchers were not commonly used lay terms. Careful consideration was given to how questions would be phrased, allowing respondents language to come through without suggestion or bias, but without simplifying things too much and risk being patronising.

### ***Language***

The first item on the topic guide was concerned with the development of an appropriate language or vocabulary for discussing outcomes with people who may previously be unaccustomed to the concept. Many terms are frequently misunderstood or interpreted differently by health professionals who use them interchangeably and so it seemed quite possible that lay people do not understand these terms in the same way, or what is expected of them. Methods of communicating these and other ideas may therefore be an important focus for further work so identifying appropriate approaches would be essential.



### ***Participation and decision making***

Outcome measures have been developed with the implicit assumption that participation is a 'good thing' and that patients would obviously want to be involved in their care. However, there is some evidence that patients do not always want to be involved in decision making and that although they wish to be consulted and informed about treatment and care, they may not want to be actively involved (Waterworth and Luker, 1990). So these concepts needed further exploration: do older people want to participate in their care planning and at what level?; are they willing participants or reluctant collaborators? What are the barriers to participation? Are there any factors which may hinder people articulating their views?

These categories formed the basis of the initial topic guide. This guide was, of course, open and dynamic. The purpose was not only to explore if what people in the groups were saying was consistent with findings in the literature, but also to see if there were any different, new concepts arising. The topic guide was therefore amended in the early stages.

### ***Revising the topic guide***

After the first two groups it became apparent that people do not conceptualise health, and health outcome, in the same way as health professionals and so further exploration of which concepts and domains participants identified, and why, needed including.

Perceived relationships with health professionals became an important issue, as were issues surrounding doctor-patient communication and so this was included in the revised topic guide. Common phrases or words used in health care settings were also not appearing, and so this confirmed the need to further explore this area.

The role, format and amount of information required also arose and how people interpret this was discussed. People’s knowledge of their circumstances and how much they wanted to know was an issue.

Methods of empowering the patient and their carer to determine what they want to achieve for themselves, and how, or if they prioritise particular process and outcome, should they wish to, in the rehabilitation process was difficult to tackle in a group situation. How do people decide what their priorities are? But it was still an important issue and so was included in the topic guide. Attitudes to coping were also important. Also, how do older people adapt to living with chronic illness and what coping strategies do they and their carers adopt.

**Table 10 The focus group topic guide**

<b>Knowledge</b>	lay versus professional - the role of knowledge
<b>Vocabulary</b>	technical expressions; jargon; understanding, meaning of explanations
<b>Power</b>	and empowerment; issues surrounding legitimacy
<b>Information</b>	what information is needed by patients and carers, what form does this take?
<b>Consultation</b>	what would participants like to be consulted and informed about, at what stage and where should this takes place?
<b>Involvement</b>	the degree of involvement in care and at what stages in the care plan
<b>Participation and decision making</b>	what level of active participation
<b>Choice</b>	what do patients and carers perceive they need to make a choice

The final topic guide, which was to be used for groups 3 -8, is shown in table 10.

## **Focus group dynamics**

### **Details of focus group participants**

Eight focus groups were convened over a period of eight weeks. Twenty five people participated in total. Two groups were interviewed on two separate occasions. These groups were shorter in duration but were also particularly good groups in terms of the quantity and quality of the data they generated. Each group had a maximum of nine members and each focus group lasted for between one and two hours. Details of the participant characteristics of the focus groups are summarised below.

The proceedings were tape recorded, with the group's prior consent, to facilitate transcribing the discussion and analysis. The groups did not have the topic list in advance of the meeting - they had been told by the group organiser that the study was based at Newcastle University and had the study information sheet. The total number of individual group members was 25.

#### ***Focus group 1 (interviewed twice)***

9 group members; 5 female, 4 male. The duration of the meeting was 2 hours. 9 people were caring for older relatives (7 spouses over 60 years, one son caring for mother - all caring at home).

Many of the participants had not met before and so the atmosphere was not always relaxed and some members withdrew from the discussion and appeared to be uncomfortable discussing other people's personal experiences and circumstances, and did not volunteer details of their own.

#### ***Focus group 2 (interviewed twice)***

7 group members - all over 60 years, 5 female, 2 male. 3 females caring for mothers, one caring for mother and husband in same home.



This was a less homogenous group and there was a wide variety of lifestyles, circumstances, age and care experiences. Although the majority of people attending the group were over 65 or were caring for someone who was over 65, there were a few members of the group who were younger, who were caring for children under the age of sixteen with cerebral palsy and were reluctant to participate as they felt they had little to contribute. The atmosphere was relaxed and members appeared to be comfortable discussing personal experiences and circumstances. The majority of the participants were carers, female and caring for an older relative living at home.

### ***Focus group 3***

9 group members, 6 female, 3 male. Duration of meeting 1.5 hours. All caring for elderly relatives, all participants over 60 years, one relative in hospital.

It was difficult to identify what was happening in this focus group. The members of the group held in this centre knew each other quite well. This was established in the opening conversation, when one lady explained that they all met once a week to share experiences and give each other support and members valued this. This was confirmed when there were nods of agreement from everyone around the table following this statement. One person especially dominated the conversation, answering questions, even when they were explicitly directed at another group member. It was felt, therefore, that this was seriously biasing the groups responses and the group were reminded that it was important to let others speak and allow people to think about what they wanted to say as it could take some people longer than others to volunteer an opinion. This tactic worked for approximately ten minutes, but the same person then re-asserted their authority on the group and again this person was explicitly asked to let others speak for themselves. This was a difficult decision to make as she had many valuable opinions, and was articulate, contributing immensely to the content of

the interview and by offending her it could potentially stop the flow of the interview. However, it was important that everyone in the group had equal say. This particular lady, however, did not seem at all offended, and interestingly attempted to switch roles from active participant to an additional moderator. She proved skilful at involving most participants, especially the quieter members who had, up to that point, contributed little to the overall discussion, and this helped the process immensely. It was again difficult to know what to do for the best. The dilemma was should the facilitator re-assert their authority on a 'deviant' group member? Or should they accept that this was facilitating group dynamics and therefore let it go ahead? After a few minutes, the group members freely and seemingly happily discussed the items listed on the topic guide, and introduced further concepts themselves. The group members seemed increasingly comfortable once they 'got into the flow' and it became difficult to know when to start to bring the discussion to a close.

#### ***Focus Group 4:***

8 group members, 7 female, one male. Patients at day hospital. All over 75 years.

The aim of the initial discussion was to try and focus on what aspects of life were important to individuals in the group. This was to try and illicit what they valued and to see how values differed amongst the group. The discussion in the day hospital group centred around health. This was a group of people who had recent or current experience of health services and the discussion started with a discussion of their problems and continued along this vein.

#### ***Focus groups 5 and 6***

These focus groups were not successful. In focus group 5, one of the group members was particularly distressed following an unrelated incident that

morning. The discussion was started, but it soon became clear that it was not going to be possible to continue, as this individual was very upset and it seemed more appropriate for the others in the group to listen to her and offer their support. The group was abandoned.

In focus group 6, only two people turned up for the discussion. This was disappointing as considerable effort had been made to organise the venue of the groups. However, it was felt that it would be more appropriate to interview the people who turned up individually, and they were the first of the focus interview participants.

### **Focus group discussion**

Some time (approximately 15 - 30 minutes) was spent at the beginning of each session, talking about 'house-keeping' activities and introducing the topics. For example, what time people had ordered taxis or asked friends or relatives to collect them to give an indication of how much time was available to help with the structure and timing of each group. This was time consuming, but considered necessary and was a useful exercise in starting to get everyone chatting. Each discussion began with general introductions to help enable people feeling comfortable about participating. In each focus group the discussion was difficult to 'get started' and even more difficult to keep 'on track'. Some of the focus groups were being held in a familiar forum to the carers who came to share experiences and 'unburden themselves' of everyday concerns and worries - particularly distressing circumstances or situation that they may want the other members of the group to know about before they could focus on other topics in hand. If the topic was unfamiliar, people kept trying to divert to more comfortable, familiar ground. Finding a balance between allowing this to take place and keeping a focus on the purpose of the group was at times difficult.



Obviously in several of the groups people already knew each other and this introduced some difficulties.

A summary of the main research findings from the focus group were sent to individual participants, who were asked to return the summary with their comments if they did not agree with the findings, or they were not representative of our discussion. Seven sheets were returned, but no comments were made.

## **Discussion**

The focus groups were useful in generating a wide range of broad themes and issues, for further exploration in focus interviews. However, it was difficult to probe for further details in such a group setting and some people appeared reluctant to discuss personal circumstances.

There were also problems with forceful group members who dominated the discussion. This was felt to be a problem directly resulting from holding focus groups where participants already knew each other and relationships had already been formed. This biased the discussion considerably, and meant that some participants did not contribute very much to the discussion.

With hindsight, it might have been more appropriate to hold the discussions in a neutral setting and ensure that participants as far as possible did not know each other to minimise the risk of this happening.

However, the majority of the participants in the group appeared relaxed and comfortable. A distinct benefit of using groups where participants know each other is that the situation may be less threatening and individuals may feel more secure and less isolated.

## Chapter 8

### The Focus Interview Study

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#### Focus interview process

The purpose of the focus interviews was to provide a forum in which older people could discuss their views about outcome. Issues and themes which had been generated in the focus group discussions informed the content of the topic.

These issues were discussed in greater detail with individuals.

#### Approaching participants

Once it had been decided to select participants from the day hospital, it seemed that the opportunity to be theoretical about sampling was actually increased. The screening interview was used with some participants in order to ascertain whether or not the particular characteristic or relationship on which sampling was based was present or not. Inevitably, screening in this way meant that a number of people were disqualified from the focus interviews. Three people were excluded from the interviews as a result of this screening interview. Some consideration was given to how to cope with the possibly disempowering aspect of this. Participants reactions were noted in a reflective diary, as the screening interviews were not tape recorded. The reasons why they were not suitable to take part in this particular piece of work was explained.

Five people refused to take part. Two people refused immediately and would not give a reason for this, but stated that they would just rather not be interviewed,

two people said that they felt too ill to be interviewed, and another refused after what was involved was explained as she said she did not have time.

In order to facilitate theoretical sampling of people attending the day hospital, people were grouped on the basis of known characteristics - age and gender. From the day hospital attendance lists and case notes, it was possible to identify people's age and gender and gather background information before the initial interview.

These were rather arbitrary groupings aimed at facilitating starting the process of theoretical sampling. The purpose of grouping people in this way was to allow selective sampling to maximise the number of categories opened up in the data. It also meant that a form of theoretical sampling could proceed in a logical and ordered way.

In reality, such crude categorisations that were developed had little meaning. Through the use of theoretical sampling, it was possible to pursue lines of enquiry within relationships until an understanding of the range of difference and similarity had been achieved. This however, led to an imbalance in the number of interviews with different groups of people.

## **Facilitating interviews**

Each potential participant was initially interviewed at the day hospital. Participants were shown a hospital identification badge along with an identification badge from the University. The purpose of the study was explained, and that it was they themselves that would be interviewed. Why and how they had been selected was also explained. At this stage, it was stressed that the study had nothing whatsoever to do with their attendance at the day hospital or any health and social care they had been or would be receiving, that



the interviewer had nothing to do with the hospital and that the study itself was a research study and separate. The participants were asked if they would be willing to take part in the research. All participants were assured of confidentiality. At this stage, permission was sought from each participant to tape-record the interview and the form of the interview was briefly explained. Once participants had agreed to take part, they signed a consent form, and a suitable date and time was arranged, to fit round the participant's existing commitments. The time and date of the interview was written on the top of an information sheet (appendix 1) which explained the study in more detail and which was given to each participant to keep for their perusal. This also contained a list of contact names, telephone numbers and addresses, should any problems or questions arise. Participants were asked if they would prefer to be interviewed at the day hospital or at their own home. All but one participant preferred to be interviewed at home. There is evidence that people feel more comfortable in their own home and more 'in control' over the process. The interviewer then checked the person's address and where deemed necessary requested directions. Two people telephoned to query involvement in the study. One participant's daughter rang to enquire what the study was about and why her mother was involved. After a brief explanation she appeared satisfied to go ahead and it appeared that the concern had been on the daughter's part not the participant. Another person rang to say the time previously arranged was no longer convenient and asked if it would be possible to rearrange.

The day before the interview was due to take place, the interviewer (LC) telephoned the participant to ask if the date and time was still convenient. The purpose of this was to check that they were still happy to participate and to ensure that they had not made other plans in the interim. Everybody in the study had a telephone (this was a co-incidence, not a sampling criteria) so not being

able to contact them was not a problem. Directions, and the time and place of the interview were also confirmed.

### **Issues of confidentiality and anonymity**

At no stage in the research process did anyone else have access to the file which linked respondents to their tapes or transcripts. Each tape was labelled with the respondents pseudonym from the beginning. Although respondents' were offered the chance of listening to their tapes or reading the transcripts, no-one took up this offer. Why this is might be is interesting in itself, but their reasons for refusing were not followed up.

There were issues throughout the interviews of trust, and issues of the unequal relationship between participants and the interviewer. 'Informed consent' was also an important issue and it's meaning in this setting needed consideration. It was difficult to know which and how much information to give to potential participants in order to ensure they had information about the study objectives, and their role in it, with which to make an informed decision about whether to take part, but without biasing the research by introducing concepts. The issues surrounding shared meaning and language were therefore important. It was also necessary to think about the assumptions which are built in to this entire process and the values which the researcher brings to the interview. For example, what does the 'researcher' call themselves, and what judgements might a person make about this and will it influence their responses? There are also ethical issues here in that if the researcher conceals their background in any way, is this misinforming people and therefore detrimental to trust? Similarly, participant's were assured of 'confidentiality' and 'anonymity'- that the discussion would be transcribed and analysed only by the interviewee, and that their account would be anonymous in the presentation of the research findings. However, their

interpretation of the term 'confidential' was not explored - it sometimes seems that assurances of confidentiality can appear to be 'professional speak' for "trust me".

## Changes to the interview process

When trying to select the first participants, the standard introduction mentioned that the author was based at the Centre for Health Services Research, University of Newcastle upon Tyne. This did not appear initially to present any obvious problems. However, after the first three interviews it became more apparent that these participants began the discussion in response to the opening remark "Tell me a little about yourself" by specifically by discussing the *problems* that they were experiencing because of disease or illness related factors, and also discussing in detail how long they had been attending the *day hospital*, along with the details of their 'treatment' there. It was difficult to gauge whether this response highlighted a genuine desire to focus on such issues which may well have been a genuine concern and priority that was central to their world at the present time. They may have held strong feelings about health related issues and health might have been a priority concern at the forefront of their minds. However, the *questions* that they asked were related to which *hospital* the project was based at, despite the fact that it had been explained in the standard introduction that the project was University based, and no hospitals or potential links to hospitals had been mentioned or hinted at. From this, it was felt that it was possible that some participants were linking the 'health' in Centre For *Health* Services Research with the hospital setting, and that this was introducing bias, albeit interesting bias. Given that previous studies suggest that people's responses are influenced by the setting and the evidence for public/private accounts (Cornwell, 1984; Goffman, 1971) this initial finding already suggested



that it was possible that people were giving responses which they perceived might be preferred or wanted. The interviews took place in peoples' own homes, where it is suggested that people feel less intimidated, but potentially it is their perceptions of who the interviewer is and where they are from that influences their responses. It was decided that in order to be able to discuss issues in a more neutral terms, then the day hospital might not be the most ideal place to contact potential participants. However, in order to develop approaches to person-centred outcome measures for people working in rehabilitation settings, it was still considered necessary to talk with a group of people who were currently receiving services and/or treatment in rehabilitation settings for a range of chronic illnesses. The day hospital, as discussed previously, is a useful place to contact such a group quickly, given restricted time and resources.

Following all this decision, the initial introduction was altered slightly to include no reference to the department (CHSR), but only to the University of Newcastle. If participants asked specifically which department, then they were told honestly which department it was, and that it was part of a PhD study. They were also told where their name and address had been obtained from and why these sources were used, before gaining consent to participate in the study. This approach does not eliminate all potential bias, but it was felt to that it was better than people immediately assuming in the first instance that it was *expected* that they focus on and discuss their *health*, at the expense of other topics which are more 'self-generated'.

If asked, the staff at the day hospital were also asked to stress that the study had no connection with the day hospital. It was difficult to tell what older people and their carers assumed though, and it was necessary to rely on interview skills and the build up of a relationship within the interview in order to dispel the connections.

### ***The role of gender***

As the interviews progressed, the interviews with male participants were increasingly problematic in the way that they articulated their circumstances.

Men seemed less prepared to talk about their circumstances in great detail, and tended to concentrate on either purely medical terms, or describe their experiences in terms of the structural aspects of care provision. It was very difficult to move beyond this in any of the interviews carried out with male participants. The emphasis in these accounts was on routines, organisation and management. Whether through lack of skills as an interviewer, or because of the socialisation of men, it was felt that a full account of their experiences or of their thoughts and feelings about their circumstances was not being achieved. Other explanations for this were sought, and it could be that, either as an interviewer, or as a woman, it had been difficult to elicit responses that under different circumstances may have been forthcoming. However, on reflection it seemed more likely that men actually construct the way they think about their circumstances in a different way to women. It also seems likely that they found their personal circumstances more difficult to talk about. Komarovsky (Komarovsky, 1962) in her study of marriage, found that the second most common reason given for men for areas of 'reserve' within their marriage related to finding it 'hard to talk about such things' (Komarovsky, 1962). 'Such things' related to feelings 'about myself'. The ways in which women are 'muted' by male structures is well known (Ardener, 1989), but the reverse, men 'muted' by female structures, is much less explored. The problems of female researchers interviewing male respondents include the fact that the content of the interviews is shorter, more formal and was characterised by a marked reluctance for self-disclosure (McKee and O'Brien, 1983). Cornwell (Cornwell, 1984) also highlights the differences in accounts between men and women. In this study, however,



differences are put down to the very real differences in the experience of community rather than to a fundamental and perhaps intrinsic gender bias in the way that people express themselves on different subjects.

## **Emancipatory (person-centred) interviewing**

Within a framework of grounded theory, there was the opportunity to adopt a person-centred approach to interviewing respondents. The paradigms of research interviews are often dictated by the objective/subjective dichotomy.

Within a positivist framework, the 'proper' interview appeals to the values such as objectivity and detachment whilst the 'poor' interview is seen as comparing subjectivity and involvement. Central to the 'proper' interview is the development of a hierarchical relationship in which the interviewer takes control of the interview and of the information to be elicited. This is also true of many structured outcome measures. Once a respondent has agreed to be interviewed, they are expected to abide by certain unwritten rules. They are invited to take part in the illusion of a conversation in which they impart information, but are discouraged from asking questions. Within this model, respondents are expected to be passive, submissive, honest, co-operative, and willing participants in the research process. For their part, interviewers are expected to be detached and 'friendly' without being 'too friendly', avoid the tendency to disclosure, and parry rather than answer questions (Oakley, 1981). Although interviewers are human beings and not machines, there is the requirement that each interview should be identical so that the information received is untainted by external personalities or subjectivity's and so provide a basis for comparison. In order to elicit the maximum amount of information from each respondent, the interview is surrounded by an aura of friendliness or 'fictitious sympathy' (Stanley and Wise, 1983; Stanley, 1993). This may be a little harsh, but the process is certainly not value free.



As with other types of interaction, interviewees may respond differently to the control exerted by interviewers within the research context. For those people who believe reality to be more complex than pre-codes or yes/no responses, these techniques will seem at best frustrating and at worst insulting. There may be socio-economic differences here too. Feminist interviewers have questioned whether it is possible to have a study in which the interviewer has no impact on the respondent at all, and therefore the value of maintaining this research hierarchy (Stanley and Wise, 1983). In the normal course of human relations, the content of an exchange is maximised where the relationship is non-hierarchical and where there is a tangible quality of empathy present (Stanley and Wise, 1983). There is a growing body of opinion that the goal of finding out about people is often best achieved when the interviewer is 'prepared to invest his or her own personal identity in the relationship' (Laslett and Rapoport, 1975) p968). It is in those situations in which interviewers are detached that the artificiality of the situation is emphasised.

To counter the impersonality and so called 'objectivity' of positivistic research methods, feminists have a tradition of placing subjectivity firmly on the research agenda (Gelsthorpe, 1992). Feminist researchers recognise that they become a part of the social world that they study and so look for ways of recording it. This does not necessarily mean that subjectivity is adopted at the expense of rigour. Rigour consists of honesty about theories and methods used, takes gender, as well as race, class and age into account and makes no claims about the absence of bias (Webb, 1984; Stanley and Wise, 1983). From this perspective, methodological rigour involves making the research process and the role of the researcher explicit (Hammersley and Atkinson, 1983; Hammersley, 1992).

As a 'young' researcher (professional, white, female) interviewing 'older' participants, it was important to be aware that this fact may introduce inequalities.

There were also differences in social class, educational differences, and life experience. Can a young person truly understand the experiences and perspective of an older person?

For several reasons the interviews did not progress along the lines of 'having a little chat' (Scott and Porter, 1983). Firstly, although the same general areas were covered in each interview, as the interviews progressed they became more focused around personal experiences of growing older and living with chronic illness. These themes were arrived at from reading the literature and from the data gained from the focus groups. Although the respondents influenced the overall direction of the interview, the interviewer did interject and ask questions and so was, in some senses, involved in creating the direction.

Secondly, the idea of 'a little chat' implies superficial or trivial conversation. Interviewing can be an intensive and stressful experience, for both the respondent and the interviewer. Participants in this study were discussing emotional issues and there were frequently upsetting occasions. Feelings of resentment, futility, anger and sadness about their situation were expressed. For this reason, the flow of the interview was led by the respondent themselves. Many of the participants felt that the interviews were therapeutic in that for many it was the first time that anyone had shown an interest in their views and how they felt:

*No, it was no bother, I'm not in any hurry. I enjoyed talking to you ... It's not something you have the chance to talk about, I've never really talked it through, you know, what happened and that*

(13;4;2)

Unprompted for much of the time, some respondents talked at great length, and seemed to come to an understanding about themselves and their situation through the process of interviewed. It is sometimes difficult to tell if participants



felt that they had revealed too much, but on the occasions when two visits were made there was not an impression of embarrassment or resentment attached to any of the previous visits. Only in one situation where the person interviewed was alcohol dependent was there any hint of embarrassment, but she did not volunteer any reference to this, and as the interview progressed smoothly, the issue was not pursued (there did not seem to be any firm theoretical basis for altering the approach to the analysis of her interviews). Indeed, when a respondent blatantly avoided a topic by completely changing the subject, it was difficult to probe further. It was also difficult to interrupt to ask a question; an answer to one question gave rise to many more. In the majority of cases the first interviews lasted for two to three hours. Often the changing of the tape was the only evidence of how much time had passed. As the interviewing progressed, respondents were offered the opportunity of deferring further questions to a second interview.

By this time there were many more questions than answers, and there was also a feeling that the participants were only beginning to discuss pertinent issues and themes. It takes time to build rapport with participants. The interviews could be intense, and many of the participants were tired after three hours. Some also had other commitments. Also, after listening to the tapes and transcribing them, additional questions emerged. Grounded theory seemed to suggest that each interview was comprehensive and that any questions raised by the data could either be answered from the original interview transcript or within the context of another interview. However, this really did not seem to be the case, and so it was decided to interview the participant more than once, where necessary, with the principle of maintaining the integrity of the participants experience and getting a thorough and as complete account as possible.



The issues of repeat or multiple interviews, other than in longitudinal or cohort research is rarely discussed as a research technique. It may stem from the idea that the gathering of structured information is best achieved at one time and in one go. It may be easier to remain detached in a one-off interview.

Five interviews had been carried out by the time it was decided to return to previous participants to ask them if they would consider a second interview. This seemed a success and later participants were asked as a matter of routine if they would mind if the interviewer returned once the tape had been listened to.

A second interview was helpful, then, in helping to gather additional information. They were also helpful in allowing the first interview, if necessary, to be shortened. But perhaps most importantly, they enabled areas of uncertainty to be clarified, often by giving the participant an interpretation of what they had said, as a technique to validate what they had said. This also lent further meaning to their accounts.

Control in the interviews is a complex matter. It is not as straightforward as just letting respondents talk about their experiences. The interviewer can experience a range of emotions: guilt because they do not share their experience of life and a sense of discomfort because of a lack of power to change their circumstances or offer them anything substantial. In a fundamental way the interviewer is always in control simply because they can walk away from the circumstances.

Occasionally the experiences of other participants, unnamed, were shared with participants, when it was perceived that they may find this helpful. This was a way of showing empathy in a set of circumstances in which the interviewer could offer little personal experience.

***Presentation of the interviewer***

Little attention was given to the interviewer's dress for the interviews. This may have been an oversight, as people's perceptions of a person might influence the content of their interview. For each interview a similar skirt was worn; motives for doing so related to perceptions about the people being interviewed and beliefs about an 'attitude of respect' that dressing in this way would convey. In part, this was intended to look respectable and to minimise offence. It seemed appropriate to be casually smart in order to instil some confidence in the respondent. It was not until the interviews were nearly complete, however, that whether attire affected the content of the interviews in any way was considered. It may have highlighted differences between the participants and the interviewer by giving a persona of 'young professional', but having not pursued this topic with participants, it is impossible to tell.

The interviews were conducted in people's homes, and no attempt was made to exclude other members of the family: spouses and children, unless the participant specifically requested or made the decision to be interviewed alone. During the interviews, there were often frequent interruptions, breaks for tea, phone calls, visitors.

Each interview was planned and spaced to leave several days between interviews to allow time for the previous tapes to be either listened to, or ideally transcribed. This was to ensure that key themes emerging could be fed into the next interview, and that the participants selected for interview could be theoretically sampled.

## Chapter 9

### Analysing qualitative data

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#### The purpose of qualitative analysis

an attempt to present and represent the social world and the perspectives on that world, in terms of the concepts, behaviours, perceptions and accounts of the people studied

(Miles and Huberman, 1984, p17)

Much of the material collected through qualitative methods is invariably unstructured and unwieldy. A lot of the material is based on verbatim transcriptions of discussions or interviews, or field notes or other written documents. Also, the material is very detailed, including accounts of experiences, descriptions and observations and so the qualitative researcher has to provide some coherence and order, while retaining the form of the original account.

Qualitative data analysis is essentially about detection, and the tasks of defining, categorising, theorising, explaining, exploring and mapping are fundamental to the analyst's role

(Richie and Spencer, 1994, p26)

There are three broad stages to this:

- ordering and developing a thematic framework
- summarising and synthesising data- for which there are a range of *tools*
- interpreting and abstracting for which there are a range of *processes*



## Functions of qualitative analysis

The points below show the functions of qualitative analysis which will obviously vary depending on the research question being addressed. These include:

- *Defining concepts*: understanding internal structures
- *Mapping the range*: the nature and dynamics of phenomena
- *Creating typologies*: categorising different types of attitudes, behaviours, motivations etc.
- *Finding associations*: between experiences and attitudes, between attitudes and behaviours, between circumstances and motivations etc.
- *Seeking explanations*: explicit or implicit
- *Developing new ideas, theories or strategies*

As compared with both the quantitative analysis of data and the actual collection of data by qualitative analysts, the methods for qualitatively analysing materials are rudimentary. They need to be developed and transmitted widely and explicitly throughout the social science community

(Strauss, 1987, p44)

In this study, a method called 'Framework' was used for the analysis.

## 'Framework' analysis

This method was devised by a specialist qualitative research unit - the Social and Community Policy Research unit (SCPR) in London. It was devised to facilitate applied policy research, which forms the core business of SCPR. This next section draws heavily on a description of the method in 'Analysing Qualitative Research' by Bryman and Burgess (Bryman and Burgess, 1994).

One of the common criticisms of qualitative research is that it is not always clear how the findings have been obtained. A method like 'Framework' provides an explicit, visible method to the analysis, and seemed to provide a useful structure for analysis in this study, while staying faithful to the broader principles of ensuring that the findings were grounded in the data.

The method has certain key features which were central to it's development.  
These are summarised in table 11.

**Table 11 Key features of analysis method: 'Framework'**

<i>Grounded or generative:</i>	it is heavily based in, and driven by, the original accounts and observations of the people it is about
<i>Dynamic:</i>	it is open to change, addition and amendment throughout the analytic process
<i>Systematic:</i>	it allows methodical treatment of all similar units of analysis
<i>Comprehensive:</i>	it allows a full, and not partial or selective, review of material collected
<i>Enables easy retrieval:</i>	it allows access to, and retrieval of, the original textual material
<i>Allows between and-within-case analysis:</i>	it enables comparisons between and within cases to be made
<i>Accessible to others:</i>	the analytical process, and the interpretations derived from it can be viewed and judged by people other than the primary analyst.

Ritchie and Spencer in Alan Bryman and Robert G Burgess (eds). *Analysing qualitative data* (1994) Routledge, London.

'Framework' involves a number of distinct, though highly interconnected, stages. Some of these stages logically precede others, but there is no rigid order. And while it is systematic, 'the method still relies on the creative and conceptual ability of the analyst to determine meaning, salience and connections' (Richie and Spencer, 1994, p27).

The approach involves a systematic process of charting and sorting the material, according to key issues and themes in five key stages summarised in table 12.

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**Table 12 Stages of analytical process**

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- Familiarisation
  - Identifying recurrent/important themes
  - Indexing
  - Charting
  - Abstraction
  - Search and interpretation
- 

***Familiarisation***

This stage basically involves gaining an overview of all the material - including becoming familiar with the range and diversity of views, setting key issues and emergent themes in context. Even when the person doing the analysis has been involved in the interviewing, it is likely that the recollections will be selective and partial (Richie and Spencer, 1994), and so this stage is particularly important.

Familiarisation essentially involves becoming emerged in the data, listening to the tapes, reading the transcripts, studying observational notes and listing key ideas and recurrent themes. It can be possible to review all the material at this stage, for example, where a few interviews have been carried out. However, researchers often have to be selective, and in these cases it is important to ensure that a range of different cases, sources and time periods are reviewed.

***Identifying a thematic framework***

During the familiarisation stage, the analyst is not only gaining an overview of the richness, depth and diversity of the data, but also beginning the process of abstraction and conceptualisation (Richie and Spencer, 1994). While reviewing the material, notes are made, the range of responses recorded and recurrent



emerging themes noted. Once this material has been reviewed, the analyst returns to the data and 'attempts to identify the key issues, concepts and themes according to which the data can be examined and referenced. He or she sets up a thematic framework within which the material can be sifted or sorted. When identifying and constructing this framework or index, the researcher will be drawing upon a priori issues (those formed by the original research aims and introduced into the interviews via the topic guide), emergent issues raised by the respondents themselves, and analytical themes arising from the recurrence or patterning of particular views or experiences' (Richie and Spencer, 1994).

Categories become more refined and responsive to emergent themes as more transcripts are examined. The first version of an index is often largely descriptive and heavily rooted in a priori issues. To refine the categories, the researcher looks for conceptualisations which encapsulate and represent diversity of experience, attitude, circumstance etc.

The process of devising and refining a thematic framework involves both logical and intuitive thinking. It involves making judgements about meaning, about the relevance and the importance of issues and about implicit connections between ideas. It also means ensuring that the original research questions are being addressed.

### ***Indexing***

"Indexing' refers to the process whereby the thematic framework or index is systematically applied to the data in its contextual form'. All the data are read and annotated according to the thematic framework. Indexing references are recorded on the margins of each transcript by a numerical system which links back to the index, or by a descriptive textual system based directly on the index

headings. When creating an index, it is necessary to draw on both the topic guide and the interviews in order to identify key themes and topics within them.

Again, applying an index is by no means routine, as it involves making numerous judgements as to the meaning and significance of the data. For each passage, the analyst must infer and decide on its meaning, both as it stands and in the context of the interview as a whole, and must record the appropriate indexing reference. Single passages often contain a number of different themes each of which need to be referenced: multiple indexing of this kind can often begin to highlight patterns of association within the data (Richie and Spencer, 1994). This is quite common and to find that different major topics are connected and interwoven is one of the values of indexing and is crucial in seeing patterns in the context in which they arise. This process of making judgements is, of course, subjective and open to differing interpretations. However, by adopting a system of annotating the textual data, however, the process is made visible and accessible to others, who can see how the data are being sifted and organised. The index is systematically applied to all transcripts, but it is possible to be flexible in the use and adaptation of the index. For example, categories might be collapsed or new categories created. In these cases, the changes are noted, but the transcripts are not re-indexed.

### ***Charting***

'Having applied the thematic framework to individual transcripts, the analyst needs to build up a picture of the data as a whole, by considering the range of attitudes and experience for each issue or theme. Data are 'lifted' from their original context and rearranged according to the appropriate thematic reference. This process is referred to as charting' (Richie and Spencer, 1994, p29)

Charts are devised with headings and subheadings which may be drawn from the thematic framework, from the original research questions, or according to considerations about how best to present and write-up the study (Richie and Spencer, 1994). The way the charts are laid out depends on whether the analysis will be thematic (for each theme across all respondents) or by case (for each respondent across all themes):

where a thematic approach is adopted, charts are drawn up for each key subject area, and entries made for several respondents on each chart. The ordering and grouping of the individual cases may be linked to characteristics or dimensions that are known or believed to have a significant effect on patterns of experience or behaviour etc. The essential point, however, is that cases are always kept in the same order for each subject chart, so that the whole data set for each case can easily be reviewed. Where a case approach is used, one or two charts may be drawn up for each case, with subjects recorded in the same order.

(Richie and Spencer, 1994, p30)

Each passage of text, which has been annotated with a particular reference, is studied and a distilled summary of the respondent's views or experiences is entered on the chart. The level of detail varies, but the original text is referenced so that the source can be traced. Also illustrative passages for quotation can be referenced at this stage (Richie and Spencer, 1994).

### ***Mapping and interpretation***

Once all the data has been sifted and charted according to key themes, the analyst begins to pull together key characteristics of the data, and to map and interpret the data set as a whole. Although emergent categories, associations and patterns will have been noted and recorded during the indexing and charting phases, the serious and systematic process of detection now begins.

At this stage in the analysis, the key objectives and features of qualitative analysis are considered again, namely:

- defining concepts



- mapping range and nature of phenomena
- creating typologies
- finding associations
- providing explanations
- developing strategies etc

Again, which of these is attempted is guided by the original research questions and the themes and associations that have emerged from the data.

whichever route is followed, the basic processes are the same: the analyst reviews the charts and research notes; compares and contrasts the perceptions, accounts, or experiences; searches for patterns and connections and seeks explanations for these internally within the data. Piecing together the overall picture, is not simply a question of aggregating patterns, but of weighing up the salience and dynamics of issues, and searching for a structure rather than a multiplicity of evidence.  
(Richie and Spencer, 1994, p31)

This is the most fragmented, although the most crucial, aspect of the process, one which does not follow a set process but is characterised by leaps of intuition and imagination.

### ***Defining concepts***

In the course of charting references to a particular phenomenon, the analyst may well have begun to identify a number of associated features or descriptions.

However, the data are now analysed to search for specific concepts or themes.

### ***Mapping the range and nature of phenomena***

A core function of qualitative research is to identify the form and nature of a phenomenon, and where appropriate to map the polarities. By reviewing the charts for references to attitudes and experiences it is possible to highlight the key dimensions. For example, it may be possible to highlight processes, systems, attitudes, behaviours, decisions or judgements etc.

### ***Creating typologies***

Having identified key dimensions or characteristics of particular social phenomena, the researcher may decide to move on to multi-dimensional analysis, as in the creation of typologies, where two or more dimensions are linked at different points, giving a range of the *types* of cases.

(Richie and Spencer, 1994, p32)

### ***Finding associations***

In the course of indexing and charting interview material, the analyst may become aware of a patterning of responses; for example it may appear that people with certain characteristics or experiences also hold particular views or behave in particular ways. At this stage, the analyst will systematically check for associations between attitudes, behaviours, motivations etc., either those made explicit by respondents themselves or those derived from implicit connections.

(Richie and Spencer, 1994, p33)

### ***Providing explanations***

Explanations may be explicit or implicit. Throughout, the analyst must look for explanations as to *why* something occurs; the reasons, causes and sources etc.

A common objective in applied qualitative research is to explain, as well as illuminate people's attitudes, experiences and behaviour. Explanations may be sought in order to address the questions that triggered the research in the first place, or to account for issues and patterns of behaviour which arise from the research itself.

(Richie and Spencer, 1994, p34)

### ***Developing or identifying strategies***

One of the key objectives of qualitative analysis is to develop strategies or ideas, theories and hypothesis to inform a wider debate.

Much of the research carried out in the... field has a strategic component; policy-makers, commission research into attitudes, behaviours and experiences because they wish to inform their policy decisions. As a result of the process of analysing qualitative data, and identifying underlying motivations, patterns and explanations, it may be possible to develop strategies for change which arise directly from the qualitative material itself.

(Richie and Spencer, 1994, p34)

### ***Summary of 'Framework'***

'Framework ', then, as a method needs to be adapted to suit the needs of the individual study, and its aims and objectives. It is useful for both group and depth interviews and therefore was appropriate to use. The next section describes sections of the analysis specific to this study.

## **The process of qualitative analysis**

### ***The reflective diary***

Immediately following the end of the discussion or interview, notes were made in a reflective diary or on a dictaphone. These included immediate feelings about how the discussion had gone, including any participant's behaviour, or body language which may have contributed to the discussion but which may not be easy to pick up on from the transcripts. Immediate thoughts and ideas on the content were also included, especially noting any interesting themes, or aspects of the discussion which it was felt might be useful to include in the subsequent discussions.

This reflective diary was kept throughout the process of interviewing and analysis but was particularly useful with the focus interviews. In this ideas, questions, quotes, instinctive reactions which had risen directly from the interviews were kept. It comprised of three broad sections. The first set of notes, were responses to the person interviewed. This comprised a description of each participant's physical environment, what they were wearing, how they spoke and any particular mannerisms or characteristics that were striking. Any interactions between the participant and other people in the house were also noted.

The second set of notes related to questions that had arisen out of something specific that had been said in the interview. These were, in the main, questions that could not be answered from the interview information. Sometimes, after



going through the tape, gaps were evident as occasionally, a line of enquiry had not been pursued to its logical end.

The third set of notes related to general research questions and analytical points. These had either arisen from a particular interview or from more general thoughts and feelings about the direction of the research.

Initially, it was not clear how these notes would help with the analysis. However, they served several purposes. At one level, they enable the person analysing the data to visualise the setting in which the interviews took place and retain an image of the people interviewed. They also provide a record of how the development of ideas and analysis over the course of the research progressed.

### ***Transcribing***

It was initially intended that each interview tape would be transcribed on the day the interview was carried out. However, the process of transcription proved so time-consuming (all the tapes were transcribed by the author) that a different method had to be adopted. As the essence of grounded theory involves the concurrent collection and analysis of data, and this determines the theoretical sample, each tape was *listened to* on the same day as the interview and detailed sets of notes were made including any key themes and issues which were emerging, along with extensive verbatim quotes. A coding sheet was constructed for each participant and attached to the front of the transcript. Wherever possible the interview was transcribed in full on the same day as the interview, but this was only possible on the shorter interviews. It was prioritised that all the tapes of the interviews were transcribed within four days of the discussion; to transcribe them immediately was the only way that ideas remained fresh. Also, with the focus group discussions it was possible to recognise different individuals from their voices. Transcribing the tapes meant that the

discussion was listened to again, and it was possible to add tone and pauses, and accompanying gestures, which may be significant but not noticeable from a written transcript.

The full transcripts of the interviews were then read thoroughly first, to become familiar with the content. Themes were then first identified by marking anything of interest in the margin with one pencil line. Comments and questions were written in the margins and possibly important quotes were underlined, all in pencil at this stage. The pencil was significant only in that it represented 'first points of interest' at this stage before the formal process of coding began.

### ***Coding the data***

Owing to the short delay in transcribing each tape, the coding took place in two discrete phases. Where participants themselves provided their own interpretation of their behaviour, thoughts, experiences or feelings in terms of 'concepts', this concept was used as the conceptual category and was marked with an asterisk.

As expected this process produced an enormous range of codes. As soon as the full transcripts were completed for each interview they were re-coded. In practice, there was a delay (1-5 days) between the initial coding of each participant's interview and the production of the full transcript for detailed analysis. Thus, although the interviewing and the coding of transcripts took place concurrently, the focus was not on the same participant. In each case, the more detailed analysis of the transcript was done directly on to the transcript by highlighting and underlining sections of the texts and writing accompanying notes in the margins, in line with 'Framework'. The purpose of this re-coding, independently of the initial coding, was to see whether new codes emerged and which codes previously identified did not re-surface. Once the transcripts had

been re-coded they were compared with the initial coding sheets to assess the level of congruence. On the whole re-coding generated many more codes, with only a small proportion of previously identified codes not being picked up. Those codes not picked up through work on the transcript usually turned out to be no longer appropriate in some way and were usually subsumed in another code or dropped. Going back through the transcripts in this way, rather than just transferring the previously identified codes on to the transcripts, facilitated considering the information and the concepts which were being identified and named in detail.

In line with the analytical progression in grounded theory from the specific to the general, the conceptually similar codes were then grouped together. Beginning with the first transcript, the codes were allocated a different number and this formed the basis of the coding. Codes of the same 'type' were given the same number. Eventually, all the codes and their corresponding numbers were transferred on to an index.

Unlike the discrete process of open and axial coding suggested by Glaser and Strauss, once coding had begun, codes and categories often emerged together. In order to structure this process, and from the beginning capture these codes and themes where they occurred, the concepts were mapped or charted. This was an attempt to diagrammatically present the relationships between the concepts and themes; a way of visually 'mapping' the concepts and codes.

Charting in this way was a helpful way of looking at the concepts. However, the concepts that had been identified and labelled often spanned more than one of the categories and they were not of the same nature as those codes and categories that had emerged together. The relationships between concepts also changed over time as analysis progressed. Accounts began to be grouped



together, but as a result of constantly checking back and forth between transcripts and concepts and codes, these groups did not remain static. The analysis, then, included a process of refining linkages and categories.

Theoretical saturation is seen as the rationale for when to stop interviewing (Glaser and Strauss, 1967; Corbin and Strauss, 1987; Strauss and Corbin, 1990; Strauss and Corbin, 1990). This is when no new themes are emerging. In reality, the decision to stop interviewing is a compromise: the amount of research time available against the extent to which new, or significant, codes or concepts are emerging.

It is difficult to make fully explicit the process by which these indexes and charts were transformed into text. The process of analysing the data was done both formally and informally. Formally, the transcripts were coded using 'Framework', and recording thoughts and ideas in a reflective diary as time progressed. At an informal level, the meaning of the data was discussed with colleagues and friends. In part, then, the route through the data, although heavily grounded in the data, resulted from constant interaction with the data at both formal and informal levels. Throughout the interviews and subsequent analysis and the writing up of the research, decisions were made about what was important and what was less important, what stayed in and what was left out. This was of course, mainly influenced by the interactions with participants. So, although every effort was made to ensure that the selection, interpretation and development of ideas was firmly rooted in the data and reflected the views of the participants, in the context of this thesis, the description or interpretation of the data is privileged. The author alone had the power to decide how the analysis of the research was presented and what has been left out. (Cotterill, 1992) argues that:

she (the researcher) interprets the accounts of those whose lives are being researched; she presents her results to an audience which is largely inaccessible to the person she has interviewed

(Cotterill, 1992, p605)

It was felt that the practice of interviewing participants more than once provided an opportunity for the interpretation of their accounts to be validated. It is also anticipated that on completion of the thesis a final summary of the findings will be sent to each participant.

## Chapter 10

### Themes emerging from the focus groups

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#### The focus group findings

##### *Older people as consumers of health care*

Changes in the culture of health care delivery have had widespread impact and influence on health care professionals. While patients are referred to as 'clients' or 'consumers' of health care, lay members of society have not been as involved in this process and are subsequently not as aware of the changes that have occurred (Long, 1996). In discussions, the term 'consumer' was met with confusion and many participants seemed unable to conceptualise this new identity, referring to themselves as 'patients'. Participants felt that they were unused to 'having a say' in services and some people remained unsure of what role they were expected to play and were unaware that their views were wanted.

Changes in the health care system have affected health care professionals immensely, and although patients' and their carers' views are now being sought, lay members of society have not been as involved in this process and are unaware of what is happening. Recent research suggests that many older people still aspire to the traditional model of medicine and are not comfortable with being asked to prioritise and be more directive over their own care (Waterworth and Luker, 1990). These are unfamiliar concepts. The findings from the focus group discussions certainly supports this view. However, the *reasons and explanations for why this is the case* are complex and there is immense variation between individuals which needs to be further explored.



### ***The meaning of participation***

Lay participation in health care and social care is fundamentally concerned with non-professionals being involved in the delivery of care (Meyer, 1993). This can be in terms of making decisions about local or national policy (Entwistle *et al.* 1998; Doyal, 1998) or at a more individual level in terms of involvement in their own care. Conceptual confusion surrounds the term 'participation' (Brearley, 1990) (Ashworth *et al.* 1992); it is used interchangeably with terms such as patient involvement, partnership, and collaboration (Jewell, 1994), and with issues surrounding professional-patient communication (Ley, 1988; Haug, 1981). It overlaps with concepts such as 'empowerment', 'shared decision-making', 'information sharing' and goal setting. This lack of conceptual clarity and clear definitions highlights the need for further theoretical, as well as empirical, work on lay participation.

Greater individual participation is increasingly advocated as an ideal model of care (Goodare and Smith, 1995; Popay and Williams, 1996), with the view that active lay participation in health and social care services will help promote greater autonomy and choice over treatment and service decisions, and encourage reliable services with focused effective outcomes of importance to individuals and those caring for them (Long, 1996).

In this study, the meaning of 'participation' was unclear to participants and meant different things to different people: some held positive views about participating, others were indifferent or more negative. Most of the participants had never considered the concept before, and so were thinking about and forming their views as the discussion progressed. Older generations are often more compliant, are more likely to aspire to traditional models of medicine and are not comfortable with being asked to prioritise and direct their own care (Cassileth *et al.* 1980; Waterworth and Luker, 1990), preferring to be passive recipients.

They appear unwilling to assume an active role in clinical interaction and, in general, are less likely to want detailed information and to actively participate (Deber, 1994). Many older people have traditionally been part of a paternalistic health service, a model which explicitly assumes a passive role for patients in decision-making processes (Charles *et al.* 1997). They may be unused to being asked to take a more active role, although caution is advised in treating older people as a homogenous group since the diversity of older peoples' experiences, beliefs and attitudes militate against such a simplistic approach.

Several meanings of what participation meant to participants emerged.

### ***Participation as patient-professional interaction***

The relationship with health professionals was important and some felt that participation to them was being able to discuss their problems with health professionals and to feel that they were listened to:

*It's just nice to have someone there who knows a bit about you and your situation ... and who you can talk to ... I can tell him how we're feeling*  
(4,17,8)\*

### ***Participation as trusting in professional judgement***

Participants who felt that they trusted health professionals felt more secure and subsequently seemed to be more positive about the benefits of participating:

*I mean you have to trust them, don't you? You have to think they know what they're talking about and will tell you what's best and feel that you can tell them if you're worried about something*  
(1,7,14)

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\*The numbers next to the quotes refers to interview; page number; line number

### ***Participation as taking greater responsibility***

Some participants perceived that greater participation meant increased responsibility and felt that they had enough responsibility in other areas of their life: taking on more would be too much of a burden because of how they were feeling:

*I'm on my own, since my husband died three years ago now, and I have to make every decision on my own, every little decision, from the bills and the garden to what to have for tea and I get very tired of it... So in a way the last thing I want is to have to think like that when I come here (hospital)*

(1; 17;10)

### ***Participation as achieving compliance***

Others interpreted the concept as compliance, and participating in terms of 'doing what you are told', suggesting a hierarchical relationship with health professionals:

*'I was told to do exercises when I was watching the telly, with my leg, like this, like doing my homework ... but yes, I suppose I do my bit and that helps her'.*

(4; 25;9)

### ***Barriers to participation***

The focus groups highlighted a range of barriers to participation by older people in their health care. Many different theories have been suggested to explain the differences in individuals' willingness to participate. Lay participation is generally viewed positively by both health professionals and lay people (Brooking, 1986), but greater participation may not be welcomed by *all* patients (Jewell, 1994; Waterworth and Luker, 1990; Margalith and Shapiro, 1997).

### ***Lack of knowledge***

Participants' were disinclined to take a more active part because of lack of knowledge:



*well, he's the doctor, isn't he? He knows. Who am I to say?*  
(5;22;2)

*... they're the experts, and so what they say goes really. I know nothing about it really, so I leave it to them*  
(3;15;4)

### ***Burden of caring***

Participants who were carers felt they were too unwell to take on more responsibility because participation of this kind would compound the problems associated with their condition:

*I just wouldn't feel well enough to take all that on now. I feel too ill, I'm too tired. I'm exhausted just, you know, living each day as it comes, and I don't need any more to worry about*  
(3;19;8)

Some authors have cautioned against the assumption that people who feel very unwell will relinquish the opportunity to take an active role in their care (Biley, 1992; Trnobranski, 1994). Indeed, Trnobranski (1994) makes the point that peoples' reluctance to participate could also be because of fear of repercussions or because of individual's low self esteem and lack of belief in their ability to make decisions. The results from this study confirm these suggestions.

### ***Lack of self confidence and belief in own knowledge***

There were differences in the groups with reference to individuals' confidence in their own abilities to make decisions concerning themselves and their carers. The reasons they gave for their feelings differed. Some people focused on how unhappy they were with being '*on their own*' in terms of not being able to share responsibility. They perceived that a situation where they were asked to participate was intimidating and that if asked to participate there would only be '*one chance to get it right*' and felt that if they made the wrong decision, the consequences would be damaging and have major (negative) repercussions. Indeed, they had little confidence that they were capable of making the right

decision. This perception was based on their own feelings, of low self esteem and sense of self worth. The participants who shared this negative view of participation clearly perceived that the final burden of responsibility would rest with them. This confirms research which suggests that an increased sense of responsibility through greater involvement, in turn can increase anxiety if the individual feels responsible for decisions (Beisecker and Beisecker, 1990) and is anxious that the decision they make is the wrong one (Margalith and Shapiro, 1997).

*I chew things over me, I don't worry when I'm there, at the hospital, I'm all right then, but when I get back I sit on me own and I chew it over, what they've said and that and what I said, and I worry about if I've done the right thing*

(11;23;25)

This individual was coping with an immediate crisis, which she could not see beyond, and asking her to step away from her situation, and 'participation' meant, in this example, think about what she needs in a more abstract form. What has been called the 'rational evaluator' (Charles *et al.* 1997) technique, is just not feasible.

Participants expressed a lack of belief in their own knowledge and capabilities and lacked confidence to put their views over to health professionals. Thus even when participants recounted past experiences where they had been unsure or had misgivings about the advice or information that they had been given, they had not voiced their concerns:

*I didn't think what he said was right about our Bill, I didn't think it would work but I'm scared of putting his back up. I mean if I start fussing it might effect Bill ... and that might be bad, do you know what I mean?*

(3;25;15)

There was also an issue of 'taking the consequences' and even those who wished to be involved more actively in their care expressed discomfort at making decisions without the doctor:

*There was one time last year, round about June, when Jim was in hospital, he'd had another funny turn and they took him in for tests and thought that he'd had a couple of strokes, not big ones, lots of little ones, not like the first one he had. And he was a little shit, he was, he had us all running round in circles cos he wanted to come out but the doctor said that he could come out if he really wanted to but they thought he should stay in another week while they do more tests. So what do you do? I didn't know whether he'd have another funny turn or what. Anyway, he would have it, so he came out and we got him home, then he was back in the next day and well, since then what they (the doctors) say goes*  
(3; 14;6)

There was an issue here of challenging medical advice and power, but having to take the consequences.

*I'm not sure about making any decisions on big things, like, I'm mean that's their job, but I just like to know what's going on, what's going to happen*  
(3;36;15)

Few people had the courage of their own convictions to go against the doctors in this way.

### ***Professional authority and hierarchical structure of health and social care***

While some participants were keen to participate and to share their views, they did not feel able or that they had a forum where they felt comfortable about doing so. This indicates that some older people do not feel empowered to challenge medical authority, and the relationship between health professionals and themselves as patients or carers, was still considered to be hierarchical, with health professionals being very much in control. This hinders participation.

Even in the few cases where people were very keen to have a greater role in planning care, they felt inhibited by the structures of the health and social care system and unsure about how the system worked.



*I'm with him (husband) twenty four hours a day, seven days a week, I think I should have say in what's happening ... but who do you tell? I don't know who's in charge*

(3;26;7)

### ***Paternalism and tokenism in professional behaviour***

Several participants felt that while they were consulted about many aspects of their care, this was more to get them to agree to what had already been decided, and that their wishes were not taken in to account:

*I said that didn't want anyone coming in to do cleaning and that, I said I could manage, but they still sent somebody*

(4;8;3)

Clear value judgements were being made on behalf of the patients. There were interesting mixed responses to this issue. An obvious split was apparent in one group, with members accepting this as 'just the way it is' and others angry and wanting to take further action.

Professionals appear to have difficulty relinquishing the paternal role, suggesting that health professionals pay mere tokenism to the concept of empowerment (Brownlea, 1987) and rather than offering empowerment, use lay participation as a means of manipulation towards compliance (Brearley, 1990) .

For some participants although the thought of having to participate further was anxiety provoking, this was countered by the fact that in reality, they believed that they would not be expected to and that their involvement was 'tokenism':

*...I think it's nice that they ask you if what they are doing is okay, I think it's nice that they think to say to us... well they know what they are going to do before they get to us, don't they?*

(5;16;3)

Individuals who were currently attending hospital for treatment, felt that there was nothing to discuss because they did not perceive there were any alternatives.

This awareness that although they were consulted, it did not necessarily mean anything, had dangerous repercussions in lack of trust, and significant implications for future active participation by patients.

Participation is a process, as well as a goal. 'Participation means getting involved or being allowed to become involved in a decision-making process or the delivery of a service or the evaluation of a service, or even simply to become one of a number of people consulted on an issue or matter' (Brownlea, 1987). This concept of 'being allowed to' implies that patients have traditionally had more submissive roles with health professionals largely controlling the processes of care. Lay participation constitutes radical changes in practice (Meyer, 1993). Health professionals accustomed to a 'paternalistic' role would have to rethink their approach and develop more supportive and facilitate roles (Meyer, 1993), including adopting a more patient-centred approach to care, one which is holistic and takes account of the perspective of the individual.

### ***Disempowering environments and experiences***

Participants' who knew a little of each other's circumstances discussed different scenarios and discussed what they felt they needed to do. A distinction was drawn between participants being able to see the potential solutions for others' problems, but finding it harder to see a clear solution to their own:

*We've all got a lot to say about what other people should be doing, but it's not the same when it's you in the middle of it*

(2;35;21)

Participants felt that at the time they were expected to make decisions, and participate in planning the next stage of a treatment plan, they were often coping with a crisis and did not consciously detach themselves from the immediacy of the situation and think rationally about what was needed.

Reasons for this included the fact that participants felt that they did not know what was happening, or would be happening, and this made them feel insecure. They felt they had to trust and rely on the health professionals involved to guide them through and make sensible decisions on their behalf:

*You have to trust them, don't you, you have to, you have to trust them, or where would that leave you? You have to think they know what they're talking about and will tell you what's best and feel that you can tell them if you're worried about something*

(1; 7;14)

A key theme was that of information seeking. All groups felt that it was important that the doctor listened to what they had to say. Participants considered that it was important to be aware of 'what's happening' and to be aware and informed of what might lie ahead. At no point did anyone suggest that they had some control in directing what happened. However, there were different desired levels of involvement.

Some participants' confidence had been undermined by apparent trivialisation of their early concerns by health care professionals, and strategies to get their concerns taken seriously frequently failed, with some people fearing being labelled 'a nuisance' or 'trouble-maker'. One woman caring for her husband described her experiences before her husband was diagnosed as having Parkinson's disease:



*... I said what I thought the problem was, I said he's not right, he never was like this, but he (the doctor) just said it was old age and not to worry*  
(2;7;14)

*I was worried, but we were there for his foot and I thought 'God, if I start going on about this and that and everything they're going to think we've got a right one here*  
(2;9;7)

These participants seemed to think that these experiences would limit their desire to become further involved in the future.

### ***Conceptualising health and health outcome***

#### ***General points in discussing outcome***

One of the original research objectives was to establish what people understand by the term 'outcome'. It was clearly not possible to simply begin by trying to discuss 'outcomes' with participants; they appeared to puzzle over what was meant by 'outcome', and this proved unintelligible to some participants, in this context.

Mostly participants expressed their views in concrete terms and not in the rather generalised language of outcomes. Some participants especially in the carer group, were very focused on specific crises or coping and managing a specific set of problems in their lives, so it was difficult for them to address questions about outcomes. Indeed, there was resistance to the idea of discussing outcome, as they saw it, because of feelings that nothing can make a difference:

*what is the point, it's a waste of time, there's no point dwelling on the what ifs, its just too depressing, it won't happen (carer)*  
(1;7;14)

*you have to make do with what you've got, day by day, don't think about the future (carer)*  
(2;8;3)

Any discussion of outcomes in these circumstances could appear abstract and unrealistic. Participants tended to frame their priorities around the improved support that they would like, such as more help with the house, or someone to relieve them from the burden of caring.

Participants found it difficult to prioritise, as they perceived their preferred outcomes to be unavailable, and therefore it was a negative exercise in dreaming about what could be. When priorities were discussed, participants tended to be less focused explicitly on personal physical or emotional well-being, but more in terms of the conditions and circumstances that they want for their lives, for example having family and friends around them were among the choices made. They referred to broader issues of 'quality of life' (Fallowfield, 1990). This carer made an implicit link between her needs and support.

*If I could get someone in more to help with the beds and the big jobs, I'd be pleased with that*

(4;17;9)

*I'd like someone to come once a fortnight even to look after Arthur while I went to my daughter's*

(4;18;3)

The challenge remains then to further explore techniques to enable people to contemplate outcomes separately from their problems while making the connection between them.

It was difficult to get participants to talk about the *differences made*. This is an important area to discuss as one of the problems common to all approaches is linking the intervention to the outcome. Participants found this concept very difficult indeed, and it was an uphill struggle to discuss it. They constantly tried to seek more comfortable ground, and began to list what services they thought were useful and what the problems were. During the interviews, an attempt to

rephrase the questions on outcomes as what can you do now, that you couldn't do if... worked with some, but others still found it difficult to grasp.

### ***Language and vocabulary***

The discussions offered an opportunity to gauge participants' response to the outcome terms used in professional practice and literature. When people are unused to expressing views they are hindered by a lack of a common vocabulary and different interpretations. Very few commonly used terms by health professionals and researchers were mentioned, and even then their particular meaning had to be clarified. In many cases the understanding of terms in the health profession and the understanding of the users seemed to be different. For example, 'rehabilitation' was not understood and the term 'outcomes' was unintelligible.

Explanations for this could include that health professionals and researchers have invariably had years of training in their particular fields, in which they become accustomed to learning and jargon, using certain phrases such expressions and terminology become common place and the meaning is 'taken for granted'. Expressions such as 'process', 'environment', 'outcome measurement' become the norm, and it is assumed that this use of language, which is used by all, is understood. Yet there are still differences in intended meaning.

Language is obviously vital in communicating and in negotiating. However, the focus group discussions suggest that many older people do not relate to much of the language used. Many of the phrases quoted above are unfamiliar and misunderstood or not understood at all. This is of particular significance in developing outcome measures for older people. Many of the outcome measures currently in use rely heavily on similar phrasing and technical words and



categories such as walking, bathing, etc., the standard areas of activities of daily living, but even these may be interpreted differently by different individuals. This affects the meaning, an individual's response and ultimately the validity of the outcome measures. People may have opinions about what they would like to happen or achieve, but they may find articulating views difficult.

It became apparent in the early stages of the first meeting that a major problem was expressing terms in lay language without introducing bias by giving the interviewer's own interpretation of a word or phrase. Participants did not understand much of the terminology used, such as 'knowledge'; they put different meanings on words, other than their intended use in this context, e.g. 'power'. A particular example is how to begin to discuss the issue of empowerment. This is an important concept to the research and central to the development of a patient-centred outcome measure. Yet it was obvious that the word was not clearly understood by most participants.

### ***Value laden concepts***

Terms such as 'independence', choice', 'participation' and 'dignity' are value-laden and subjective concepts: those interpreting responses impose their own moral and political judgements. It was interesting to note some of the differences that occurred: terms such as 'choice' and 'dignity' were regarded in a negative light and talked about with some hostility as people perceived they did not have a choice or had not been treated with or did not have dignity for a variety of reasons.

### ***Seeking information and support***

There is evidence that people want *information* about their health and health care and wish to be consulted and informed (Cassileth *et al.* 1980; Waterworth and Luker, 1990; Biley, 1992), but preferences for the type of information, timing and

amount differ widely (Degner and Sloan, 1992; Hack *et al.* 1994). Reasons for this are as diverse as the range of settings and groups of patients with which these studies have been conducted.

### **Awareness**

When discussing the care that they were receiving, participants commented that it was important to them to be aware of the overall process of events:

*I like to know what's happening, and what's going to happen*

(3;36;4)

More specialised information needs appeared to be linked to specific health problems, such as suffering a stroke, or heart attack:

*When I first heard that he'd had a stroke, they said he'd had a stroke, I'd heard of them but wanted to know about what it meant and that. I wanted to understand what was going on*

(3;21;7)

But having information about the full range of possibilities available to them was also important. One of the problems identified was that there was a lack of choice:

*Yes, but what you don't understand is that people like us haven't got a lot of choice, the only choice is take it or leave it*

(3;14;7)

Yet some participants felt they had received more information than they actually wanted. One man recounted that the doctor told him he would be involved in a minor operation to treat a leg ulcer. The man was more interested in the outcome, less in the process:

*I thought: why are you telling me all that? Just get on and do what you need to do. As long as you get it sorted, that's all I care about. They do go on*

(2;19;4)

Obtaining satisfactory information about their situation or the person they care for, was very important to participants, and was vital in helping them cope (Cassileth *et al.* 1980; Waterworth and Luker, 1990; Biley, 1992). However, the type of information they received varied immensely in its style and accuracy and there were cases of a noticeable lack of support. Most communication seemed to be entirely verbal, the quality depending upon the method of communication and the ability of the informant to make the message clear. Also, the amount of information required by different patients varied immensely, both in terms of the quantity and the times when they required it.

It is well documented that patients want information (Ley, 1982). This was obviously true, but while certain conditions and chronic illnesses such as stroke and heart disease, are well documented and there is a wide range of accessible literature available, other chronic conditions are less well-documented.

*They can't have three hours with everyone explaining this and that, can they? They haven't the time*

(4;13;7)

Interpretation of the discussion suggested that a good understanding of their circumstances or situation was significant as it provided individuals with the confidence to participate more fully in their care, when they knew the options available. In turn this helped to minimise their feelings of anxiety.

There was a general lack of understanding of the full range of services available.

### ***Relationship with health professionals***

During the focus groups, the discussion centred around negative past experiences of poor relationships with doctors, and it was a struggle at times to keep the discussion focused on the role of the doctors and not to deteriorate into



a session of 'doctor bashing'. Participants valued health professionals who listened to what they had to say and took their wishes into account.

### ***Professional hierarchy***

Although the discussion ranged over many care environments, participants referred most commonly to doctors when recounting their experiences with health professionals. Few distinctions were made between GPs and hospital-based doctors, or grade, and this frequently had to be clarified. When participants did refer to themselves, or others they considered like them, they referred to themselves as 'patients'.

Amongst participants who recalled being asked by health professionals for their opinion, most often it seems by a doctor, there was a certain puzzlement and confusion as to why they were being asked.

### ***Assessments***

The discussion touched upon existing standard assessment instruments of which participants had experience. These included both social service means-assessment forms and standard assessment tools encountered in the hospital setting. There was frustration and resentment over the content, both in terms of the information that was requested and the way the questions were phrased to illicit this information. For example, one carer particularly expressed resentment over a Social Services assessment:

*I mean its ridiculous isn't it? Asking how many seconds it takes you to get out of bed on a morning? Ridiculous. Or how many minutes it takes you to get from your lounge to the toilet. One of them even asked me how long it took to get dressed. It's just plain ridiculous. It's different from day to day, even hour to hour. I don't know what they expect. I don't. Do they expect us to have a stop watch in our pockets all the time?*

(3;38;7)

Clearly, the purpose of the exercise had not been fully explained to this individual, who in the absence of any facts or explanation to the contrary,

concluded that it was merely a strange whim of the social service professionals. This felt patronising to those involved and trivialised what they perceived to be a major everyday problem. Patients had no concept of *why* this information was required i.e. that this was an assessment exercise and was intended to help professionals determine the patient's progress in terms of a before and after scenario. They also appeared unclear as to *how* the information would be used and interpreted: however, that this process could potentially be used to develop meaningful goals for the patient and carer to help them monitor progress did not occur to them. *Through the patient's eyes* the exercise was meaningless and unimportant.

There was a feeling that their own particular needs had not been accounted for:

*I wanted to talk to him (doctor) and I knew that I only had a few minutes and he was busy and would get annoyed and might not come back, might avoid us and so I answered all his questions and he filled in these forms - dozens of sheets wasn't there, and then I said what I wanted to say, and he said what was what but then he said he had all he needed to know there and he'd be in touch.*

(4;13;12)

Several instances had arisen whereby patients and carers had repeatedly requested services and information and, although promised, these were not forthcoming. A lack of knowledge of who to contact or what is available was evident.

## **Problems with the focus group process**

Focus groups have limitations. For example little is known about the way that effects of social desirability and conformity influence expression of views and to what extent heterogeneity of participants influences results (Morgan, 1993).

Similarly, the effects of the facilitator are not well understood (Morgan, 1993).

Also, people excluded from focus groups, for example like in this study on the

basis that they had difficulties in communicating verbally, may be disempowered because they are not deemed to be 'competent' (Holstein and Gubrium, 1995). However, this qualitative approach was useful in helping people explore and articulate views which they may not have expressed previously.

One particular problem was that people tended to dwell on the negative aspects of their past experiences and the discussion often drifted into anecdotes of short comings, and failures and away from potentially positive outcomes.

Frail people in the groups, or people with very immediate problems, did not engage as easily in the discussion and this is certainly an area to explore further. Of course, the group setting might not be conducive to this and the results may be different on a one-to-one basis. There were no extremely frail people in the groups; this needs to be countered in the focus - interviews.

But despite some problems, the discussions generally flowed well and a range of potential outcome domains and approaches to discussing outcome emerged. Different methods definitely were needed for different people. Within all groups there was considerable variation in ability and keenness to participate, attention spans, the extent to which people had immediate emotional needs to meet, the readiness with which they understood the task in hand and the extent to which they had a view to share. These differences need further exploration as the reasons behind them were not clear and were at least as important in contributing to the differences in the group process as was the type of group.

## **Summary of focus group findings**

The purpose of the focus group study was to highlight and explore some of the issues pertinent to older people for greater participation in their health care. The focus groups provided an appropriate setting for exploring participant's



perceptions, in their own words, about participating in their health care, about their needs and aspirations, their experiences of care and their priorities. The focus groups were useful in identifying and exploring themes on the meaning of participation, and involvement in health care decision-making.

Older people have diverse views. Some participants were positive about actively participating in care planning and decision making, others were indifferent or more negative. A fuller understanding of the *reasons* for these differences is necessary in highlighting barriers to greater participation, and further explanation of these issues is required.

The limited evidence from this small study suggests that it is not possible simply to embrace the concept of greater participation between health professionals and older people. To elicit patients' views takes time and skills, time that busy health professionals may not have and skills which they may not have had time to develop. Little time, and few resources puts pressure on health professionals to use time efficiently and so the experiences, and attitudes of the individual are not fully explored.

The reluctance of many participants to participate in health care-decision making, and the diversity of reasons and explanations for this, suggests that while the decision to encourage people to participate is well-meaning, the reality is very different and there are several factors which need to be in place before full and true participation can be expected.

First, language is obviously an important part in communicating and negotiating and so a suitable vocabulary for discussing both health care and outcomes of care with people who have previously been unaccustomed to the concept needs to be developed. Terminology such as 'outcomes' and 'goals' are frequently interpreted differently by health professionals, and so it is feasible that lay people

may not understand what is meant, and without a means of discussing and negotiating, meaningful treatment decisions seem less likely.

Second, information about why people are being asked to participate and how these changes have come about needs to be shared with people. The lack of information and subsequent misunderstandings surrounding the nature of outcomes and goal setting, could be demystified if appropriate information was available.

Third, the present structure of health care needs to be considered. The focus on task-oriented practice makes an individualised system of care difficult to adopt and hinders the introduction of true participatory practices. While 'new management' espouses a consumerist spirit, the structures that are in place actually inhibit meaningful participation. There is also the view that this renewed focus on *individual* responsibility diverts attention away from oppressive social structures through ageism, sexism, and racism. As a group, older people are particularly vulnerable to such social structures. The diversity of experiences of older people, which includes social class and levels of education, militate against the consumerist approach and further limit participation. Empowerment and participation come about as a result of the shift in power, an alteration of social structures, rather than changes in the individual level. A particular difficulty is that older people have been socialised into a subservient role in patient-professional interactions and approaches which focus on the *individual* risk glossing over this (Ashworth *et al.* 1992).

### ***The next stage: focus interview recommendations***

The focus groups were extremely useful. The purpose of the discussions was to generate themes for further discussion and they were successful in doing this.

The original topic areas which were chosen were shown to be appropriate areas

to pursue in consequent focus interviews. Participants in all groups found it easier to discuss concrete outcomes such as services received or not received, having enough money, seeing friends and family. Their health outcomes will also be explored. Some older people did not recognise the changing structure of the health service and the changes in service delivery. Many were unaccustomed to having a say in services, were unaccustomed to formally considering and expressing their views and perhaps most significantly, were unaware that their views were even wanted. This may have implications for the meaning and form of outcome data. Their expectations might be dulled through exposure to traditional modes of service allocation, and this was an issue which certainly needed to be explored in the individual focus interviews.

Many themes emerged and these were noted to include in the topic guide for the later interviews. Also, where further elaboration or detail might have been useful, this was noted as a particular point to include in later interviews as compensation for gaps in the data.

Many of the themes identified were taken forward into the focused interviews to explore concepts and issues in greater detail. For example, the possible underlying causes to attitudes to participation such as gender, education levels etc, needed to be explored. How people's past experience has shaped their views and attitudes may also be important, and influence individual motivation. These differences were felt to deserve further study, to try and identify factors to explain them. It was also hoped that the focus interviews would be a suitable forum to examine which factors enable or inhibit people in defining desirable outcomes and monitoring the impact of services.

There may be differences in groups of older people in their approach to health and health care objectives as people have different life histories, perceived



needs and expectations and these concepts also need to be further evaluated and explored in the focus interviews, as they may be linked in preference of approach or desired involvement. If people want to be more involved now, have they always wanted to be involved or have their attitudes changed in any way and what has influenced them?

***Summary of focus group findings and key topics to take forward to the individual interviews***

- there are different groups of older people, and many are:
- unaware that their views are wanted;
- unaware of the extent of health service change and how it could affect them;
- unused to 'having a say';
- uncomfortable about being asked to prioritise and direct their care; and
- unable to conceptualise prioritising for decision making.

## **Chapter 11**

### **Participant's methods in the interviews**

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The actual process of analysing the data was a central concern; the data was extremely complex. Using 'Framework', progression in the analysis relied upon identifying similarities and differences between the participants, based on fragmenting the individual experience. As the task of coding proceeded, this became more difficult to do in that there was a constant tension between the micro analysis of the text and a desire to maintain the integrity of each individual's account. Two aspects of the analysis seemed fundamental to creating this tension. Firstly, the deeply 'biographical stories' or anecdotes which participants used to talk about their circumstances past and present, seemed to reinforce and sustain the integrity of each individual account. At the same time, the similarities and differences between the participants encouraged analysis across several different accounts.

#### **The use of stories**

The interviews with many participants became a way of telling stories (Graham, 1984; Berger and Berger, 1976). This is not to fictionalise or denigrate the information or the way in which it was given. Contextual information woven around incidents and events, enabled aspects of personal history to be parcelled up and transported through time. Participants tended to place issues or events in their broader context, drawing on other relevant information to explain or elaborate upon particular aspects of their account. Graham (1984) suggests that

in life-stories, biographically relevant experiences are linked up in a temporally and thematically consistent pattern.

In this way, questions that were asked by the interviewer during the interview were frequently aimed at understanding a part of the 'story' which most often became the focus of another story. Through the natural inclinations of the respondents to place events in a context, and through the subsequent questions to better understand this context, participants narrated their life-story around their current identity of growing older in modern society and living with chronic illness.

The narratives traced connections between events which were located in every aspect of their life, often childhood or adolescence. Through these connections and the juxtaposition of events, participants actively engaged in constructing their own interpretations and views of their lives. Stories provided an active way of relating information, and a biographical understanding of participants emerged.

experiences are always embedded in a coherent meaningful context, a *biographical context* (my emphasis)

(Rosenthal *et al.* 1993, p62)

Life history and life story are continuously, dialectically linked and produce each other:

the present tense of the verb *to be* refers only to the present; but nevertheless with the first person singular in front of it, it absorbs the past which is inseparable from it. 'I am' includes all that has made me so. It is more than a statement of immediate fact; it is already biographical

(Berger and Berger, 1976, p370-1)

It was this understanding of growing older and living with chronic illness as a stage in the life course that created a tension when developing codes and categories.



When analysing the data, one instinct was to somehow preserve the richness of each individual account by representing it in its entirety. As the interviewing and analysis progressed, it seemed that focusing on the *purpose* of these stories, rather than just the content seemed appropriate. Although there was very little inconsistency in the telling of the same story at different points in time, the significance of a story could be altered by the context in which it was told. So, at times, the purpose of the story was as important as its content. In general, stories placed information in a particular temporal and social context, and as such their relevance was derived from their relationship with or to the subject being discussed. In this study, four ways in which stories were used have been identified:

Firstly, there are those stories that appeared to be told to justify a value statement; stories that worked as *explanations*. Secondly, there are stories that were meant to *clarify* a statement. Then there are those which appeared to be used as a way of *avoiding* a particular subject and finally there are those stories which were told in the context of other stories to provide *background* information. These stories give the impression that the respondent was 'going off at a tangent', and occasionally, the thread of the initial story was lost or forgotten. Whilst, with this typology, the stories described appear conceptually distinct, one form of story does not exclude the possibility of a diversion into another type of story, nor of one story playing a different role in the context of another story.

Justification stories appear to be offered in support of personal or value-laden statements. They were often critical of someone:

*Oh, she's a very stubborn woman. A few weeks back we had a chance, Dr Benson found her a bed and I said to her, I said, 'when you get back' I said, 'tell her there's a bed for her'. Up to then she was going in, but as soon as she was told there was a bed for her, no way was she going in*  
(4; 7; 9;)

*Well, I think there's a bit of stress, it's only natural. I mean, you see, the situation is that they think I'm like a child, I came to the stairs the other day and I heard my daughter say 'she'll have to do what she's told', and you see I don't like that, she's become bossy. It's not true, that's what I mean when I say she's wilful*

(28; 5; 4;)

In clarification stories, respondents elaborate on aspects of stories that they deemed to be unclear, unusual, incomplete or which seemed to require emphasis in a way other than repetition. These stories combine actions or behaviours with interpretation:

*I find that anything new, I panic. I had to have a new washer because the other one broke. I like to do it myself. Our Pat (daughter) said that she would do it, but I like to do it like I always have. But it's a right one, I can't get the hang of it, and the other day I put some washing on and it started to bang, bang, bang. Well, it was terrible and so I rang Pat and got her round straight away. I said 'drop what you're doing and come to see to this*

(9; 4; 17;)

Avoidance stories appeared to be used by participants as a way of avoiding talking about something that was difficult or painful for them. These stories were told within the context of emotionally distressing explanations and were, from the way in which they were told, attempts at changing the subject of conversation. In themselves, these stories are insufficiently contextualised to have much inherent meaning. Although Graham suggested that stories 'mark out the territory in which intrusion is tolerated' (Graham, 1984, p107), stories were rarely self-contained. In the telling they opened up previously unimagined avenues for questioning which would have remained unexplored had more structured forms of questioning been used. In addition the signals that participants gave in relation to 'personal information' were rarely straightforward. Participants frequently hinted at something that they wanted the interviewer to know, but did

not actually reveal what it was or talk about it at the time. Sometimes, they appeared to have second thoughts about not saying what it was, and made an explicit attempt to say something later or on another occasion. However, while in general, these stories enabled participants to retain control, they did not always draw the boundaries around information in the way that Graham (1984) suggests:

*It's a big struggle, a big struggle, but... (pauses). I've got to put those bulbs back in soon or they'll be sprouting on that ledge. They've been left so long they'll be taking root where they are*

(6; 9; 3;)

*Oh we've always been close, very close, yes. (pauses). I used to have six and twenty a week spends, that's going back a bit isn't it? I used to work when the kids got bigger at the chemist in the village*

(17; 4; 21;)

Tangential stories are those which filled in background details thought to be essential to an understanding of the main story being told. These stories cover a range of topics and appear to be connected to, or sparked off by, something that had gone before. In a sense, it appears that one story acts as a mnemonic aid for another story. Like a set of Russian dolls, tangential stories often contain within themselves other tangential stories. They add depth to a picture of everyday life, by filling in missing details from the main story:

*There's a lady across the road, Mrs Black, and she's been very good. She comes across, and we've got a lot in common, and she says 'come and have a spot of dinner with us'. Anyway, my cousin got this skin condition, it was really bad, and all itchy*

(19; 26; 30)

There then followed twenty lines of dialogue about the effect this skin condition had on his life and work before she returned to:



*What I was saying was that while he had that, Mrs Black kept popping over to see if he [cousin] and I were alright*

*(19; 27; 31;)*

Story telling was also used to provide historical explanation; to describe their arrival at their present position from a complex past. Links were traced between events and experiences overlaid with an interpretation of their significance. Relationships remained in the shadows and were only brought in if they were deemed relevant to the story. Searching back from the present, participants built on their narrative accounts, elaborating, clarifying, justifying and providing new information. Accounts changed. (Acker *et al.* 1991, p148-149) in explaining this phenomenon in their research, discuss how, over time, one respondent's 'definition of what was important' changed in the process of being interviewed. They became qualitatively different as different parts of a much bigger story were filled in. While stories placed the individual in a particular spatial or temporal location, they were not static or rigid entities. The information contained in the stories when presented in another context, provided new meanings or cast new light on previous interpretations. Multiple interviews did not appear to encourage new ways of seeing. As (Acker *et al.* 1991, p148-149) point out: 'we face live material that is constantly in the state of transformation'.

Occasionally, stories were shortened or referred to, to take account of the interviewer's prior knowledge. Where this occurred, it was recognised by statements such as 'you remember', 'as I said before' and 'as you know'. In other cases, the assumption that the interviewer did remember was made and reference to crucial participants or events was not accompanied by the additional clarification of the earlier story. This would seem to support Berger and Luckman's (1966) notion that experiences retained in consciousness are

sedimented as 'recognisable and memorable entities through which the individual makes sense of his biography'.

This suggests that people have a fund of stories, incidents or episodes which have assumed symbolic meanings in the context of their life histories.

Quotes are used extensively in presenting the analysis for both the focus groups and focus interviews as a way of illustrating the concepts or ideas behind a particular piece of analysis. Participants are identified by the first letters in the brackets, followed by the page and line number from the transcriptions. Often several quotes are used from different participants. This is not intended to lend quantitative evidence to the arguments but to demonstrate the similarities or differences between participants in the form, shape or content of their stories. However, isolated sentences, however appropriate as representations of concepts or categories of response, cannot carry explicitly all aspects of their meaning for several reasons. Utterances were frequently accompanied by gestures and emotions which are difficult to gauge from print. In addition, the interpretation of quotes, relies on a more detailed level of knowledge. Where motives are attributed to other people and interpretation placed on behaviour, they resulted from participant's perceptions and reconstruction of events.

As already stated, the difficulties experienced in actually analysing the data stemmed from the tension between analysing each account 'biographically' and analysing the similarities and differences between the accounts. As the interviews progressed, it became easier to recognise the qualitatively different explanations within the same account. These different explanations seemed to represent both a change in the relationship between the interviewee and their story, as well as a change in the relationship between the interviewee and the interviewer over time.

## Public and private accounts

In the analysis of the interviews, explanations appeared to work at different levels. There were those explanations which revealed the diversity and complexity of relationships, experiences, attitudes and beliefs, and exposed the contradictions and personal motivations associated with considering one's own position. At the same time, there were explanations, rooted in moral values, which gave different reasons for considering their position. These explanations focused on the interpretation of the position of older people in society compared to the younger groups. These accounts were couched in the language of obligation and were interesting because of the way in which they were produced. Invariably, such accounts were at the beginning of the interview. They seemed to exist in the minds of respondents as self-contained entities, a 'pat' response, which was not always well integrated with other more complex accounts. Men and women used similar language in the construction of these accounts.

As the interviews progressed and more details and complex pictures emerged, these public accounts began to appear simplistic by comparison. It became difficult when analysing the interviews to separate the *content* away from the way in which the accounts were produced. It was possible that what participants were doing when they presented different types of account was creating public and private accounts (Cornwell, 1984) of both events and the way they felt.

Although the way in which these events and feelings were explained and described at the outset did not contradict the way they later came to be constructed, there were these qualitative differences in accounts over time. It is well documented that in certain situations, an individual might describe and explain their views and outward behaviour differently (Goffman, 1971). In these instances it was very difficult to decide why this was happening.



Robert Merton (1972) notes in a discussion of 'insiders' and 'outsiders' in the research context, that different kinds of knowledge are produced according to the overall nature of the research relationship, and Voysey (1975) concluded that the meanings attributed to behaviour, or used to describe circumstances, are situationally specific and informed by the generalised concept of the public and the nature of public morality. Cornwell (1984) rejected the possibility that the differences resulted from tricks of memory or from deliberate attempts to mislead. Instead she located their origins in the nature of her interactions with respondents over time:

In the course of the research the same people gave accounts of events in their own pasts which were substantially different from the accounts that they had given of the same events on previous occasions. It seemed to me that these were not tricks of the memory, but occurred because of the changes in their relationship with me

(Cornwell, 1984, p12)

Public accounts characterised 'stranger encounters'. They comprised sets of meanings in 'common social currency' that reproduced and legitimised the assumptions people took for granted about social norms. Private accounts reflected interactions in which a degree of intimacy had been established. They describe the way in which a person 'would respond if thinking only what he, and the people he knows directly, would think and do' (Douglas, 1974; Douglas, 1976). This clear distinction between the two accounts suggests that their articulation is consciously and voluntarily controlled, and that individuals know in advance the right sort of account for the right circumstances. While there may be situations where certain accounts are given to achieve a certain end, for example, in a sales ploy, Goffman (1971) suggests that public accounts are used by the majority in situations of social uncertainty, when people are concerned about conforming with normative standards.

'Impression' management according to Goffman is 'an intentional or unintentional means of creating a desired effect which also serves to control the response of the other person' (Goffman, 1971). In everyday life, there is generally a clear understanding of the importance of 'getting off on the right foot' and 'first impressions count'. Also, though, in some cases, the desire to create a particular impression may be matched by an equal desire to keep information hidden. In her study of 'community life', Cornwell (1984) found that the 'best-face' (Laslett and Rapoport, 1975) of community, recorded in public accounts became, in the light of the personal experiences and anecdotes of the private accounts, a complex web of relationships, united and divided by circumstances.

This phenomenon of public and private accounts has been recognised in other situations. In an examination of girls' views of motherhood (Prendergast and Prout, 1980) it was found that girls could retain a 'private' view about the realities of motherhood based on their experiences with their own mother at the same time as they espoused a 'public' view of motherhood which conformed to the stereotypical views of motherhood of which they had no experience. Girls in the study also knew which account was appropriate for which circumstances.

In addition to the change in relationship that may occur over time between the teller and the tale, the tale which is told may depend on the context and the listener. It is not inconceivable therefore that public accounts may be so highly contextualised that an individual can produce different public accounts of the same phenomenon in different circumstances.

Given the content and nature of accounts produced by participants in this study, some recognition of these public and private accounts is necessary. These are in reference to participant's perceived position of older people in society, for example, ideas about rights, financial benefits, which were prominent themes,

and ultimately infringe upon how older people conceptualise their health, and social, care. The public accounts in this study reflect common social conceptions about older age, and in some ways the 'moral parameters' within which individuals as part of society, function. The private accounts, which developed over several interviews and therefore over time, detail the personal circumstances and motivations which contribute to the formation of people's accounts. These emerged as the interviews progressed, and were a product of the interview situation. In this thesis they also provided a useful analytical device by which the experiences of participants may be understood. However, whilst recognising the distinction between the two types of account, it is on the private accounts that most attention was focused, as the aim was to gain a greater understanding of how individuals conceptualised their health, and social, care and what outcomes were important to them, taking into account their individual views and experiences.

In recognition of the similarities between participants in relation to the construction of 'public accounts' all participants are discussed together. It was hard to distinguish differences between the accounts of men and women at this stage. For the purposes of presenting the results more clearly and highlighting some of the differences, the private and public accounts are separated.



## Chapter 12

### The public account

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In this chapter the distinction in the analysis of the interviews between 'public' and 'private' accounts is discussed. In their public accounts participants gave explanations which reflected the perceived prevailing social and moral norms, but also reflect an interesting combination of moral values and a sense of duty and obligation which they felt both as individuals and on behalf of society. These attitudes are helpful in beginning to understand the wider context in which people's lives are situated and what might influence people's attitudes. These factors are also important in understanding how they conceptualise, for example, need, entitlement to health and social care services and ultimately what outcomes they may value and expect.

#### Ageist attitudes

Ageism was a significant theme in these accounts. The terms participants used were largely negative - they talked in media terms of the 'problems' of old age, i.e. the problems that they perceived older people posed, both as individuals and collectively, on society, and of the 'burden' of this ageing population:

*well, it's a problem isn't it? They say that there's going to be 30 million pensioners by the year 2000... I don't know how they're going to cope*  
(13;12;8)

*...a burden on society, and there are so many, I really think something has to be done really*  
(4;15;78)

In contrast to the explanations in the private accounts (see chapter 13), participants tended to group all older people together and did not distinguish between characteristics within this group, such as age or illness, but instead assumed a common identity. Older people were stereotyped as being one homogenous group. Old age was perceived and presented as being synonymous with ill health, even if this had not been their own personal experience:

*Well, when you're old, you're always at the doctors, with one complaint, or if it's not that it's something else*

(9;21;80)

*I'm lucky I've not been that bothered myself, but of course I expect I will be because that's usual isn't it? More aches and pains and groans and grumbles!*

(21;10;47)

With the onset of 'old age', it seemed, people were destined to become ill and subsequently to become dependent on others for support:

*It's how you're brought up, you know. You live together, and you do okay. But then one day you're old... and there's nothing you can do, and you have to just get on and accept it. I mean a lot of people are selfish and just look after themselves. It's inconvenient having an old person there, I think a lot of people think that*

(16; 34;4)

Having previously provided care for other people, some of the female participants felt that they did not want their children to feel obliged to provide the same level of care:

*My mother and father were living up the road when we got married. But she took bad about six months later, so I was down there seven days a week from nine in the morning to six at night. I looked after her for near on nine year, we got a nurse in in the last few weeks. I had two homes to look after. When she died, my father came down here when he had a heart attack... he only lasted a couple of weeks after that. Six months later it was my brother with cancer, he had no-one to look after him, and so he came here as well. I would do it again, if I had the time over, but I don't think I can expect the bairns to do the same for me now, they've had so much already*

(15;11;7)

*I wouldn't want to be a burden. I wouldn't want it on my conscience, not everybody sees it like that*

(22;21;80)

This was the public account of not wishing to become a burden, and this was their motive for remaining independent.

Another feature of this section was the passive attitudes which people expressed. Whether an inherited or "learned" characteristic, 'staying out of trouble' (Waterworth and Luker, 1990) was a personal characteristic which now defined who respondents felt they were. This was conforming to ageist stereotypes of a "nice old lady" (Bond *et al.* 1990). There seemed to be belief in the public accounts that if people fulfil the expectations that others have of them, or the roles that they want them to occupy, then if they reach a point when they can no longer do this, they might legitimately be excused from fulfilling it.

*I try to be no bother to Pat and Roy and the kids. I try to keep out of their way and not bother them, they've got enough on, and ...I'm doing very nicely at present. So, I potter on ... there'll come a time when they have to do more, ... I'm conscious of that*

(1;10;47)

Implicit in this comment was a sense of obligation to look after parents and an expectation that children would inevitably care for them when they became more frail. However, some participants recognised that some people would act differently in the same circumstances:

*I mean I know somebody, her father had a stroke and he was terrible trouble. And in the end she just couldn't live with it and she left him*

(8;14;59)

## **Social conscience, resources and rationing**

Although results from the focus group discussions suggested that participants were unaware of changes in health services in terms of the fact that greater participation was required and that there was increased emphasis on



effectiveness and efficiency, participants in these public accounts did seem aware of the issues of rationing and prioritising. Alongside the view that a growing older population was unequivocally a “problem” and a “burden”, participants also showed an awareness of the strain on resources that such a population growth presents, both on the wider economy in terms of pensions and benefits, and also in terms of strain on the NHS:

*I really don't think that the country can cope with the numbers... I mean if you think of how much goes on pensions when it could be spent on things like getting people jobs, or houses or jobs. It's a problem, there's no doubt about that*

(8;21;80)

*you wonder where the money's going to come from, don't you, to keep all these people... and the money that's spent keeping us all going... tablets and medicines and that... it's a wonder there's any left over when you start thinking on it*

(14;7;38)

Participants were clearly conscious that resources were finite. They perceived it was necessary to prioritise and ration resources:

*You have to decide somehow, don't you, how the money's going to be spent and on what and well, what's going to go where. I think you have to, otherwise what do you do?*

(9; 27;16)

*There's always problems, in every part of life, they're always each wanting more for themselves but I think somebody has to decide what's going to get priority, you know what's going to get the most money from one year to the next, although ...how you decide I don't know*

(6;5;5)

The concept of need was introduced by participants, as it was suggested that funds be directed towards ‘those who needed them most’:

*I suppose you have to think about who needs things the most, you know who needs them the most*

(3;7;16)

By distinguishing between those people ‘who needed’, participants also established the possibility of a group who ‘did not need’ or who were ‘less needy’:

*There are those who need these operations and that more than others,  
always*

(4;16;17)

However, in these descriptions, a lack of value for older people was again evident, as a distinction was made between younger people, sicker people and older people who most inferred were considered a low priority:

*I think when it comes down to it, the young-uns need it more, these ones who you see who need replacements, new hearts and kidneys... They need them then they've got the chance of a whole life ahead of them*

(41; 20; 3)

This seemed at times to be an almost instinctive, pat response and a 'taken-for-granted' quality or the natural thing to say.

The defining feature of the concept of need and the 'people-who-needed' was that this was a moral issue. Having a conscience, a social conscience, was identified as enabling people to distinguish between what is right and wrong in a situation and then to take the right course of action, an obligation to do the right thing. This implied that some people would be more 'deserving' of care than others. Participants tended to generalise, to group people together, regardless of their circumstances, and to take a moral perspective. Accompanying this concept of need, there also seemed to be a subsequent judgement about entitlement and the implicit assumption was that younger people were more entitled to care than older people:

*I don't like to see young ones in pain. There was a young lad who lived in the same street as my daughter, our Ann was friendly with the mother, and she has another little one who's in the same class as our Paul, so he'll be five or thereabouts. Well, as I was saying, the youngest, Tara, she's got a heart murmur and poor little mite, she can't run... and she goes a ghastly colour, they say they go blue and my!. Well, when you see them like that... you have to make sure that they get what they need, you know in the way of help, and that they can have the operation to put what's wrong right and have the chance of a normal life*

(31; 19;24)



A basic awareness of rationing and a need to make conscious calculations was identified. For example, participants discriminated against people who needed cosmetic surgery and those who smoked:

*You can't have people with these tattoos taking money from people who have a bad heart, or need an operation. I mean it's not their fault is it, ...they have it done on themselves, on purpose, like. I would just say "no, none of that, they'll have to pay"*

(45; 7; 17)

Despite these views, they also contradicted themselves by saying that everyone was an individual and therefore health services needed to take account of personal circumstances. One participant was particularly vocal in that she believed that money should be spent on children's services and not on those for older people:

*Well, I think we've had our time, haven't we? I think we've had our time and we've got to look out for the young-uns*

(8; 6;15)

However, this was very much a public account: in later interviews this participant contradicted this statement partially, in that she questioned whether there shouldn't be enough for everyone and that older people who are ill, equally deserve a share of resources:

*Well, I mean if you're ill, you're ill, aren't you? People don't ask to be old, just as they don't ask to be ill.*

(8; 60; 3)

This issue about entitlement was tied up with other issues about reciprocity. Those being 'cared for' were depicted as being 'deserving' of care. This included abstract notions of redistributive justice and indebtedness. Here there were clear gender differences. Male participants were more likely to point out that they had paid taxes all their lives, and so 'people like them' were entitled to benefit from the resources they had helped to create, and that they had 'earned' any services or care they received:



*I paid all my life, worked from being 16 and now I think I'm entitled to get a bit back*

(39; 9;12)

*People like me, we've worked forty, fifty year to pay for the downs and outs of this country, ...scrimped and saved all our lives, ...and I think it's time we got a bit back*

(46; 13;2)

When women touched on this issue, they tended to link themselves as a unit with their husbands, even if they themselves had not worked:

*Well, I don't really know really. I mean you do feel as if you've put a bit in the kitty, my husband worked hard and we were rarely ill. He never had a day off in his life, and so yes, I suppose you could say that we've put a bit in and that*

(38; 4;16)

Some participants felt that they received more than they gave, and this influenced what they felt they could now expect. For example, one female participant who had a history of gynaecological problems felt that she had taken her fair share of resources out of the health service and did not believe she was entitled to any more:

*I had a lot of problems down below... when I was going through the change and I was in (hospital) for months... One of the neighbours had a bit of a do with his heart and they told him when he was in that it cost thousands to have done what he had done, and I thought, well if it cost that for him, and he was only in three days... what did I cost? what did I cost the country?*

(13;3;36)

There was a personal feeling of indebtedness. Alongside this notion of reciprocity was the notion of gratitude and that older people, as way down the priority listings, should be grateful for what services they received, as there were other more needy groups. Feelings of personal gratitude were also extended to health professionals for the care and attention they had received.

While participants appeared to be comfortable with the need for such judgements to be made, and discussing them in hypothetical terms, they were unsure how to decide how to prioritise care and services and ration resources in practice:

*How you decide I don't know. (pauses) It's tricky, isn't it? I don't know, that's for someone better than me*

(44;16;8)

They were also uncertain about who controlled these judgements: they differed in that most felt that health professionals, most obviously the doctors, should be the ones in charge as they were perceived as being experts:

*It's the doctors isn't it? I suppose they have all the facts to hand and can make sense of them and that*

(15;17;4)

Also, no-one was aware that such an explicitly rationed process had involved them specifically, or someone they cared for. They acknowledged the problems that clinicians face and some admitted that it was difficult to generalise, and that they would feel more uncomfortable if they were directly involved:

*Oh no, I wouldn't know the first thing about it, I wouldn't know the first thing. Best leave that side of it be*

(33;17;3)

The apparent acceptance of the devalued position of older people in society mitigated against conscious calculations about need and outcome and seemed to eradicate any involvement in the decision-making process:

*We're old, we don't need anything, we can't do anything,... we're past it now*

(33;15;8)

## **Expectations and outcome**

These issues of rationing and need were linked to expectations and outcome.

Through recognising a common identity with people like themselves, and conforming to ageist stereotypes, participants appeared to feel compelled to accept the status quo. Implicitly, and in some cases, explicitly, markers were put out to signify an alternative course of action. As Wright (1971) points out, the

essence of a moral decision is the exercise of choice and the willingness to accept that choice. Not to accept the position of older people in society in terms of competing resources, exists only as a choice for other people, people without a conscience. By using a series of personal anecdotes or stories, participants demonstrated the notion that there was an obligation to take a more passive position and personality:

*You don't make a song and dance about it do you? It's just not the done thing. I think there's nothing worse than seeing people rant and rave. Some people are like that. I'm not. I'm not hard see. I've never stood up for myself. It's not in my nature. When I was at work... there was some trouble with the wages, we didn't get the same as the other girls in the other office... it was very unfair... we felt badly done to... but we never said anything. I remember we were all on our dignity like nothing you've ever seen... very proud, ...rather than say anything.*

(19;15;1)

## Summary

The use of focus interviews with each participant provided an opportunity to understand how people conceptualised issues such as need and entitlement, and what they valued and expected from health, and social, services, in a more complex and detailed way. The freedom that these discussions gave participants, to provide their own accounts and express their own views, was helpful in exploring and interpreting many of these issues. Ultimately this gives insight and context to participants' expectations and desired outcomes. A biographical understanding of their lives was possible through the use of stories which link past and present. Ways of seeing events alter once any story is told (Williams, 1984), and the fact that most participants were interviewed more than once, meant that it was possible to move from beyond the superficial, less complex explanations, the 'public' accounts, to gain more insight into the private accounts.



Both men and women used a complex series of explanations to describe their position and their perceptions of older people in society. These are what have been termed 'public accounts'. These accounts were public in the sense that they reflected the perceived 'publicly acceptable' thing to say or do.

Public accounts centred on the interpretation of the concept of need and the devalued position of older people in terms of entitlement to resources. These accounts centred on the interpretation of the experience of being 'elderly'; participants grouped themselves with all other older people, regardless of age or personal circumstances. In this respect, they gave insight as to how they valued themselves as part of a wider group. Surprisingly, considering the negative connotations usually conveyed by such ageist attitudes, the accounts did not come across as negative. However, people did not explain their position as resulting from a positive choice, but due to their circumstances.

Social policies, as a reflection of prevailing ideology, reinforce these ideas of older people being a financial drain or burden and reinforce ageist attitudes in the way that health services are rationed and delivered (Bond *et al.* 1990).

Obligation was also a key theme, but was not used in the abstract and universal sense of 'doing one's duty' but as a personally-held morality. While reflecting prevailing norms about older people's attitudes, these accounts also included personal references and explanations. Personal conscience was pivotal to a sense of obligation. The explanatory power of this concept of obligation was crucial to understanding how people conceptualised their situation. People without a conscience had choice, people with a conscience had no choice. Building on this notion, participants emphasised the inevitability of what would happen in old age. Having previously seen others in a similar situation set a

powerful precedent from which there was little expectation of deviating. In fact, expectations seemed to be dulled because of this fatalistic view of older age.

Participants emphasised their perceived role as being passive, and made references to not wanting to be a burden and to remain independent.

Independence was depicted by many, especially women, as being the ideal, a role model in both a practical and moral sense. In these accounts the principle of a passive role and discussions about few resources for service provision, provided a way of generally describing what they expected to happen, without being instrumental in the actual making of decisions. The concepts of duty and reciprocity seemed to be a way of retrospectively justifying events and actions, and as a way of trying to explain the context in which they received services, but expected little. For this reason, the concept of duty seemed to be more important in a public explanation of older people's expected outcomes than actual decisions about what happens at an individual level.

These concepts of social conscience and awareness of rationing were useful in indicating what standards people expected. They were also useful in exploring how participants distinguished between outcomes and how they thought that need could be measured. This was a useful starting point for exploring in the interviews how users *defined* outcome.

### **Public to private accounts**

The public accounts incorporate notions of justice and conscience as ways of describing the situation in which older people perceive themselves more generally. In so doing these accounts gloss over personal tensions and contradictions, and reveal the profound embedding of ideology and cultural forces in individual realities and interpersonal relations.

As the interviews progressed, it was possible to distinguish with some participants when they were conscious of giving a public account, and were anxious to give the answer that they perceived was wanted - the socially desirable response. There were many contradictions in participants' narratives which hinted that their views might be deeper than the explanations they were currently giving might suggest. The public statements were often accompanied by glances towards the interviewer, which is obviously difficult to convey in written form, but which were interpreted as suggesting that the interviewee was seeking approval, or at least some reaction to suggest that what they were saying was the type of desired response. This could stem from a number of reasons: the unfamiliarity of the topic being discussed, a genuine desire to help the research, or a desire to please the interviewer. As mentioned previously, the public accounts came early on in the interview, and the speed with which the private accounts began to emerge varied, depending upon how quickly the relationship between the interviewee and interviewer progressed. With some participants, all male, it is actually doubtful if the explanations ever progressed beyond the public.

If these public accounts represented the truth and the 'whole story', then a paternalistic approach to care and a paternalistic approach to measuring outcome may be somewhat justified, in that they suggest that older people appear grateful to accept what services they are given, and appear unwilling to make decisions which they feel they have little right to make. However, whilst social conscience, beliefs about resources for health and social services and attitudes to expectations reported here are very real, they give only a limited insight into people's views and beliefs. Over the course of the interviews, other factors clearly influenced how people conceptualised care and outcome, and the inevitability and attitudes to growing old and to growing old with chronic illness



was, in the private accounts, replaced by a complex range of psychological, social and circumstantial factors which operated over the life-cycle. The levels of standard response across the public accounts masks the immense diversity which emerged in the more private accounts. It also masks the fact that people do have opinions about what they value and why, and also have ideas about what health and social services should be achieving for different people.

In the light of the private accounts, the public accounts appear superficial and partial, with an over-emphasis on passivity and negative attitudes to older people and growing old. The major focus of the analysis, the private accounts, illustrates the diversity of views and their sources, and the complexity of this group of people.

## **Chapter 13**

### **Introduction to the private accounts**

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While the concepts of age-rationing and entitlement may be unifying principles behind which participants publicly articulate and rationalise their views, it became apparent in the course of the interviews that participants could also describe and explain their views and experiences in many other ways. These more intricate and complex explanations had more to do with the everyday content of their lives than the all-embracing notions of morality and social conscience; the public accounts of what they expected.

These private accounts provide an important insight into family relationships and reflect personal circumstances. They illustrate the choices and decisions which people make and how they decide what is primary. These accounts describe situational and contextual factors, including the personal history of those involved, all of which help to provide an understanding of the wider framework within which older people operate.

The private accounts reveal the wide range of emotional experiences which may accompany the experience of ageing, ageing with chronic illness, and ageing with disability, along with the activities of coping. This is particularly important, as assumptions about aspects of emotional coping are frequently made on the basis of whether a person is depressed or anxious, and often fail to take account of

additional factors, such as a sense of control, or of low self-esteem and self-worth. Within this context, statutory services may need to intervene to support and assist lay individuals to develop new skills and offer a wider range of services to tackle this problem.

Within the private accounts differences emerged, in the structure and content of explanations. The private accounts comprised complex narrative reconstructions of relationships and events and experience. In explaining these, participants drew on aspects of their lives over the life-cycle and illustrate how, through time, the influences of culture and society had interacted with personal, emotional, psychological and structural circumstances to elevate the importance of certain aspects of their lives. Given this range of influences over time, it is difficult to isolate any one structural, or emotional, or physical factor and say it holds the key to how that person conceptualises outcome. Clearly, it is not that simple, and in different relationships and different contexts the same factor had varying degrees of explanatory power.

Despite this diversity, there were areas of similarity and overlap between participants. As analysis progressed, the concepts emerging were obviously complex, and there was considerable overlap. To separate them would be artificial and so organising the data in a meaningful way for presentation was a difficult task. There is considerable overlap between the chapters. This was because every effort was made to maintain the integrity and continuity of participant's accounts. This was part of a conscious decision to try and ensure that the importance of *context* to interpreting the accounts was illustrated.

The analysis is presented in two main sections. A core theme which is central to each section is the effect of institutionalised ageism on older people and how this effects their experiences, both as members of society and in health care settings.



This was the fundamental theme which shaped accounts and the centrality of this as a key theme must be emphasised in both sections and throughout the analysis. In examining the key research questions (see chapter 1) including the experience of care, people's expectations of care, if and how they make judgements about care etc, the impact of ageism, the negative perceptions of ageing combined with the effects of chronic illness on a person's self concept, are crucial to understand.

Firstly, chapter 14 explores some of the concepts and domains which participants suggested were important areas to, or factors influencing, their quality of life. These were domains identified by *all* participants. To facilitate the analysis, and to illustrate differences both between and within the accounts, participants were put into three main general groups: *empowered individuals; dominated individuals and reluctant collaborators*. These groups were formed as a result of examining participants accounts on *how* and *why* certain topics or issues were raised or discussed. In this way, the *context* of participants accounts remains core to the analysis, and ensures that the focus is not artificially skewed towards simply *what* was raised. This was to try and ensure that any themes pertinent to exploring outcomes were identified and mirrored in the *form* of what people were saying as well as including the *content* (Long, 1994).

Within the private accounts, participants had different experiences of care, according to how decisions about care, amongst other factors, were made. Issues of power and a sense of control over events were central to these different experiences, to the dynamics of the accounts, and to the private-public distinction. Within these broad headings, then, the continuity and integrity of the private accounts is maintained by analysing the similarities and differences between the different groups, and individuals within the groups, under three sub-headings. These are *negotiating control; decisions about care (including the*

*experience of health and social services*); and *relationships with others*. It is hoped that by examining the participants accounts under these headings, that the diversity of views and experiences can be illustrated, along with the *impact* that these factors can have on how a person makes judgements and ultimately may evaluate change. A fundamental core theme to the private accounts was that of control, and how decisions about care were made and how care was ultimately experienced were influenced by a sense of control. The *meaning* of control to different participants and the *meaning* of control in terms of maintaining a sense of independence is used as a canvass on which to hang some of the factors which are part of the context of how older people conceptualise outcome.

In Chapter 15 the emphasis shifts to health care and health care structures. Participant's accounts included a great deal of information about how they coped with a range of chronic illnesses. Many of these themes can be found in the literature on chronic illness. However, again the sense of the effect that institutionalised ageism has on how people cope with chronic illness and how this manifests itself in health care structures pervades the accounts. The effect this has on people's self concept and their experience of care is considered. There was a great deal of unity across the accounts here, and a shared experience of health structures. To illustrate this, the accounts are not separated into the different groups as much as in chapter 14. Participant's relationships with health professionals is a key theme. As older people are increasingly being asked to participate in their health care how they perceive themselves as part of this process, what they see as their role, is important. Some of the key assumptions underlying involving older people in their health care are explored.

In summary, the data from the private accounts are not presented as a definitive study of 'quality of life' for older people. This was not the purpose of the study. Rather it is the intention to illustrate the complexity of the context which older

people bring to health care settings and how the different influences cannot be easily separated. How older people perceive their overall situation is important to how we develop approaches to outcome evaluation in rehabilitation settings and a greater appreciation of these influences seems vital if we are to progress.



## Chapter 14

### Social construction of outcome measures for older people

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independence is generally considered to be something that disabled people desire above all else. In many ways, this is true, for if a person is excessively dependent on others then he or she must fit in with their schedules and plans, with a subsequent loss of freedom and autonomy. In addition, it is all too easy for the relationship between the helper and the person being helped to develop into an unequal one, with the helper having undue power and the disabled person being compelled to constantly express gratitude, or at best never complain. However, I believe that the notion of independence can be taken too far, restricting the lives of disabled people rather than enriching them

(Entwistle *et al.* 1998)

#### Domains for 'quality of life'

For any approach to be person-centred, it is necessary to establish *what* areas of their lives are valued by the older person. A truly person-centred approach will respect and *respond* to topics which the patient identifies as important and as having meaning to them. However, as the review of the literature on ageing and disability illustrates (chapters 2 and 4), researchers continue to make ageist, ethnocentric and sexist assumptions about what constitutes 'normal' life for people who are older.

There is a considerable literature on identifying the domains people consider important to their quality of life (Farquhar, 1995; Bowling, 1995; Fallowfield, 1994; Fallowfield, 1990) and more limited data on what older people consider important to their quality of life (Farquhar, 1995; Bowling, 1995). Older people can and do

talk about what is important to them in terms of their quality of life (Farquhar, 1995). Farquhar (1995) listed the topics that older people focused on. In order of priority, these included family and friends, social contacts, health, mobility/ability, material circumstances, happiness, youthfulness and the home environment.

Other factors which are important to 'quality of life' which are well-covered in the gerontological literature are factors such as self esteem (Schwartz and Peterson, 1979; Coleman *et al.* 1993), a sense of self and identity (Tobin and Liebermann, 1976), and a sense of control (Rodin and Langer, 1980). Such factors have been emphasised by theorists on successful ageing (Baltes and Baltes, 1990) in that they are important for people having a positive view of themselves, and impact on their relationship with family or other people, their activities, their social responsibilities, their continuing ability to manage their lives, adapt to change and see meaning in their lives. However, these concepts have been largely ignored in the literature on *outcome measures* for older people. Outcome measurement for older people in rehabilitation settings has tended to focus on narrow medically orientated definitions of health. The medical model has long been criticised for a focus on the individual, suggesting 'personal problems', which detracts from the alternative emphasis of biopsychosocial integration. The whole 'existence' of outcome measurement promotes the ideas of professional help as opposed to shared individual and collective responsibility, and supports personal adjustment over environmental manipulation, or individual adaptation over social change. The term 'care' is a medical model definition; more social models would suggest it is a human right to receive what is defined as 'care'. The data from this study suggests that a combination of these two models might be a helpful way forward. And so, a 'bridged' model would see disability as both a personal *and* a social problem, and promote, for example, a shared emphasis on personal adjustment *and* environmental manipulation, on individual treatment *and* social action.



Positivist approaches are forced to make judgements about which topics to select to deal with, and to categorise and sub divide topics. The structures of our health and social care services also mean that such approaches separate out health and social care. Thus, a person who identifies social integration an important outcome or whose greatest anxiety is the effect of their illness on their spouse, presents 'problems', as the structure of health and social care services is such that this may be difficult to adequately respond to.

The broad domains identified by participants in this study mirror many of these domains identified by Farquar (1995), Bowling (1997) and others. It is pertinent that the dominant themes identified by participants were largely psycho-social. They considered the concepts they identified were central to their ability to live independent and fulfilling lives, as they defined it. Health was just one concept amongst many others, albeit an important one. The emphasis, the meaning and the context of how the themes were presented by participants is an important distinction in the data as it tells us more about not only *which* dimensions might be worth exploring, but the *relationships between* the dimensions and the relative importance of different aspects to different participants. They are fundamental to the accounts and underpin what participants felt was important to them. In turn, they are important for understanding more about how older people conceptualise outcomes, what influences their expectations and the meaning their circumstances have for them.

The interviews sought to explore what the experience of older age meant to participants. This section of the analysis begins first with factors which participants identified as being important. These include a sense of control and related influences: issues of self esteem and self worth; confidence; a feeling of self reliance and a sense of mastery. Other important factors identified were the importance of being socially integrated and not isolated; feeling like you had a



purpose in life. Financial security, and outcomes such as personal appearance, clean and tidy homes, adequate diet and help with shopping were actually 'secondary' outcomes to these themes.

The accounts were characterised by how people's lives were restricted, both by chronic illness and by the negative attitudes to ageing in society. This chapter illustrates how the experience of growing older in contemporary society is shaped by societies attitudes to older people and the barriers in society to 'successful ageing'. The participants demonstrated huge diversity. It was intended that there would be a range of ages and genders within the groups, and a range of different socio-economic circumstances. However, here chronological age did not seem to be a factor in determining which domains participants highlighted as being important to their quality of life, although it has been shown to be an important distinguishing factor in other studies (Bowling, 1995).

What this section is illustrating is that it is not possible to focus on a person's health, without considering a range of other contributory factors, which give a person's experiences context and meaning.

## **A Sense of Control**

The concept of independence is central to the philosophy of rehabilitation services in the UK; the aim of rehabilitation is to 'restore independence' (Royal College of Physicians and British Geriatric Society, 1992). It is also a core concept underlying the development of many outcome measures (Harwood *et al.* 1994; Bowling, 1995; Bowling, 1996) which aim to assess the impact of these services.

The concept can be measured in terms of physical functioning and mobility, more in line with a medical model. Current services and in turn approaches to

outcome measurement tend to emphasise functioning and being able to perform certain activities of daily living as a means of maintaining independence for an individual. However, the concept can also be explored from a more social model in terms of autonomy, choice and *control*. In determining approaches to person-centred outcome measures, what older people value as independence, how *they* define and interpret it, what 'independence' actually *means* to participants is important and yet this is often absent in many policy statements. This concept was, then, explored in the interviews, along with how and why the concept had developed a particular meaning for participants.

An appreciation of this concept of control seems crucial to fully understanding the *meaning* of independence and a normal life for older people. It is also an essential concept in understanding how older people might conceptualise care and outcomes of care. As the concept is so pivotal, the first and largest section of the analysis is devoted to it.

In the psychological literature a sense of control is thought to be a critical aspect of psychological well-being (Rodin and Langer, 1980; Steptoe *et al.* 1991; Taylor and Ford, 1983). The essential role played by control in the lives of people has been demonstrated in terms of positive outcomes including emotional well being, successful coping with stress, health outcomes, behaviour change and improved performance (Thompson *et al.* 1991). A sense of control, specifically a threatened sense of control, may be particularly salient for vulnerable sections of society, for example, those with few resources and people with chronic disease. The onset of an incurable illness and its pervasive impact on a persons 'quality of life' can act as an unremitting source of stress, challenging self-generated perceptions of control.

Control is one important way in which individuals can differ. Thus, when faced with a similar stressor, some people cope well, whereas others fail to adjust and experience considerable distress. Control may be a contributory factor influencing variability in patterns of adaptation in the context of chronic disease. Investigation of the phenomena of control may, therefore, be an effective means of gaining insight into the process of adaptation amongst people with chronic illness. Chronic disease in general is associated with a vulnerability to depression. This combined with a sense of lack of control can be particularly damaging to a person's well-being. The care of chronic disease (chapter 4) in general involves a departure from the traditional medical model of illness. Responsibility for control of daily symptoms and carrying out treatment requirements often lies firmly with the patient. Self management consists of a continual process of self assessment resulting in behavioural choices and decisions. The behaviours necessary for self management need to be acquired, practised and mastered. Social cognition theory suggests that people's behaviour is governed by outcome expectations and incentives (value expectancies). For example, the patient must not only perceive a given behaviour as being effective in achieving reduction in pain, for example, they must also perceive *themselves* capable of successfully performing the given behaviour. However, it is necessary to first identify which aspects of the illness the patient believes are amenable to perceived control.

Control was important in this study in terms of control over life events in general and over specific treatment *processes* or services. Power has been defined as 'the exercise of control, constraint and coercion' (Bilton *et al.* 1987, p197) and control as the ability of one person to influence consistently the outcome of decisions. This definition was core to this study. Who had control over the decisions about care on a day-to-day basis, how this control had been achieved



and how it was maintained were central to how participants considered their circumstances and the services they received. The dynamics of control were influenced by a number of factors over the life cycle and were linked to their feelings on their position as an older person in society. In all the accounts there was a sense of change, a sense of dynamism, and that the control could shift at any time. In cases where these issues about control had not been resolved, there was considerable tension between service providers and participants and their families. These relationships, however, were not static, and changed over time, along with the balance of power.

## Empowered individuals

A group of participants are described as 'empowered' as they explicitly described independence in terms of choice and control and in terms of respect and autonomy. A key sociological concept is that for there to be change there must first be consciousness (Bond and Bond, 1994). These individuals were aware that they felt devalued by others *because they were old*, and *consciously* struggled against this, using a variety of coping mechanisms. This makes them distinct from other older people. This group were largely female, but there was a wide range of ages (67 to 92) and socio-economic groupings (see appendix 2). There were also considerable variations in the type and stage of chronic illness. Interestingly the two oldest participants in the study were in this group, as were two of the participants considered by the author to be the frailest, which cautions against assumptions that the 'oldest old' and the most physically frail individuals are always the most vulnerable. This group's private views came through very quickly and clearly: they tended to be more articulate in their responses and were particularly enthusiastic in participating in the discussions. This is reflected in the *amount* of data generated from participants in this group.

***Empowered individuals: negotiating control***

These participants recounted how they had recognised the importance of highlighting to both friends and relatives, and the health professionals that they were involved with, the importance that they attributed to being independent, as they defined it, and how this had to be taken into account when offering treatment (health services) and 'help' (social services). They themselves kept the balance between accepting and refusing help constantly under review. Any actual or perceived changes in their 'health' opened up the opportunity for the treatment and services to be negotiated and re-negotiated. From these participants' perspectives, this was critically perceived to be a two-way process, with *shared* responsibility. For example, with reference to certain home adaptations, they were able to, in theory, and occasionally did in practice ask for help with things they had previously not had help with. One participant expressed the view that he hoped that the health professionals that he was involved with would *offer* help with things he had previously not had help with. In these ways they felt they anticipated and successfully adapted and managed change:

*well, off course, nothing stays the same does it, none of us are getting any younger and things change. Of course they do, things change and that's something that you get used to. So I think that yes, you have to talk to people about that, ... and it's okay then*

(18;4;7)

*I said to them [doctors] that I would be staying in my own home and that we needed to think about what we were going to do about that*

(30;4;17)

Participants in this group presented themselves as flexible enough to accommodate a change in need, as well as being able to tolerate contradiction and difference. These participants seemed distinct from the rest of the participants in the study, in that they explicitly expressed a belief in the power of

explanation. They attached great value to being independent and in taking control of their own destiny. This included the concept of personal autonomy, which was contextualised as an important part of their life biography:

*maybe it's because we were so poor, but we didn't want charity. We wouldn't borrow if we couldn't afford it, and if we couldn't afford it, we couldn't have it. That was our attitude. And that's how I've always been, ... and always will be, I think. I don't think I'm hard done by*

(1;2;14)

*I'm proud, my mother was proud, we're a proud family. But I believe in knowing everything. I like to have a reason. It's no good just telling me something, I like to know why. And I say "why do you say that?"*

(30;14;6)

Reason ruled over emotion, and they were adamant about the importance of self-sufficiency and self reliance. Being independent, as they defined it, was highly valued. However, they recognised that the *meaning* of 'independence' to them was re-negotiated as they went through life. As long as they were involved in any re-negotiating, though as an equal partner in the process this could be a positive experience:

*I think so long as you know what's going on, you know, as long as you can say you're not happy, if you're not happy ... it's having someone to tell, who will listen as your equivalent, if that's the right word*

(30;15;8)

*As long as I know, you know, what's happening, what's going to happen you know, then that's alright*

(10;15;2)

They would not allow themselves to be smothered or over-directed, and when they felt that this was about to happen, they rebelled, giving examples of refusing services, even though it may mean them 'doing without':

*I won't be sat on. I like things my way and that's that*

(1; 4;7)

*Bossy bloody woman, I said "shove your bloody bath seat and shove it"*

(18;17;7)



Such attitudes came from experiences in their own life-history, often stemming from relationships they had with their own parents, but which they had carried through into adulthood:

*if ever we did anything wrong when we were nippers, and even after I was wed, if my mother didn't agree with something we were doing, she'd tell you. That's as far as it went, like. She'd never fall out with you or anything like that, but she'd pass on her opinion, and it didn't matter if you took any notice of it, but she passed on her opinion. She treated you like you were an adult, you made your own decisions and took the consequences. She wouldn't interfere but she'd give you an opinion*

(30; 4; 13)

*I think they tried not to interfere, you know when we was kids and when we got older and that. The things me and my sister did, we was wild, you know, wild, well for our time - you probably wouldn't think much of it ...but me mam and dad didn't do much to try and control us. I think they saw our mistakes as a way of learning, but at the same time they was always there for us, always*

(1; 13;1)

Two important factors emerge from such stories: that of being treated as an adult, an equal and being free to make one's own informed decisions. From this attitude of trying to negotiate control, these participants felt that they preserved respect from the people that they dealt with in the community, in shops, banks, and in more social settings. They valued this respect, but felt it was a constant struggle to maintain, without offending people. Mrs Brearley made the distinction that she was conscious that she was treated differently because of other people's attitudes towards her *because she was old*, and had clearly given some thought as to how best to respond:

*people see you and they think 'old'. And they think they should treat you differently, just because they've decided that you're 'old'. So they shout at you, they do, they raise their voices as if you're deaf, and they shout, and everyone can hear what they're saying. But then, I calmly say to them 'would you like me to speak to you as if you were a child? No, so don't speak to me as if I am, thank you very much', I say. And they don't do it again. They know better then*

(1; 13;1)

Such quotes from the accounts demonstrate the negative 'lived experience' of being an older person in an ageist society (Andrews, 1999; Blythway and Johnson, 1991; Ginn, 1993; Townsend, 1986). Although these people had developed strategies to deal with this, they felt annoyed and frustrated when incidents occurred.

***Empowered individuals: decisions about care***

There was a subtle conceptual difference between 'being able to do what you liked' and a feeling of self reliance. Most of the participants were receiving some support with certain basic household activities of daily living, such as washing, cooking and cleaning, from either social services sources, or from more informal support. However, none of these participants felt that they had made an explicit decision to receive 'care', nor were they confident about defining the help they were being currently offered as 'care'. They based their definition of care on past experience of dependency and illness. In these instances they had been confined to bed and been temporarily dependent on their family for an extensive range of personal care. As this was no longer the case, they preferred to refer to any assistance as 'help'. Help, as a concept, was generally seen as being less emotionally charged than care. Help was an everyday component of the long-standing relationships that had developed between participants and family and friends. It was a mutual, more co-operative term and endeavour than care.

At the time of the interviews, they did not define themselves as 'ill', and made a distinction between 'ill' and 'old' and between 'care' and 'help'. The nature of the process of adaptation over a long period of time was evident. Both Mrs Brown and Mrs Johnson found difficulty in identifying a beginning to 'being helped'. Rather than seeing themselves as being or becoming dependent on others, they were concerned with maintaining independence by helping themselves and felt a sense of responsibility for this. This group of participants felt they retained a



degree of control over their circumstances, even when or if they needed considerable assistance with activities, ranging from help around the home, to daily medical treatment.

Mrs Johnson, for example, had, since birth, been dependent on insulin injections for the treatment of her diabetes. Her eyesight had begun to deteriorate when she was in her forties as a consequence of the diabetes. Ten years after, it had begun to decline further and Mrs Johnson asked her daughter, who lived locally, to help her with her daily insulin injections:

*I wouldn't say that was caring, it was just natural. I'd been having these injections for sixty odd years, the only difference is that Pam was giving them, not me. I suppose my eyesight changed, but I'm just the same otherwise*

(29; 26;7)

This illustrates how Mrs Johnson adapted to her chronic illness and this change in administration of her insulin was considered 'normal' or natural to both Mrs Johnson and to her family. She attributed the change in her eyesight to her diabetes. From her accounts, it would seem that Mrs Johnson had *expected* such a change for some years, based on her experiences of coping with the condition over a long period of time. The transition of insulin administration was accomplished with minimum disruption or distress. The fact that her eyesight had deteriorated considerably over a period of six months was a significant factor to her perceived quality of life, in that she described how she was now unable to read labels and see to unwrap packages. However, in terms of coping with her diabetes, she perceived little impact and the changes that had taken place were considered part and parcel of living with diabetes. She anticipated future 'complications', but her sense of control over the situation empowered her to feel more comfortable about any changes:



*Oh, I expect there'll be something else one day, more complications, there always is. For example, I had a lot of dizzy spells a few years back, when my levels were all over but again you get used to that. You just expect the unexpected I suppose you could say*

(29, 19;8)

This illustrates that any change in her physical condition is best interpreted in the context of how she herself perceived the impact. Where decision-making was reached through negotiation, in a mutually supportive atmosphere, people anticipated better outcomes in that they were optimistic about change and, perhaps more importantly, about *dealing* with that change. Independence was valued and in mutually supportive, companionship type relationships succeeded through the shared values of independence. They had not been encouraged to become dependent on carers, either as a sole source of social contact or of help. These people actively facilitated the inclusion of other people in their lives. Within this context, neither disability nor frailty were translated into dependency.

The concept of autonomy was important. Indeed participants defined independence as 'being able to do what you want, when you want, how you want'. The importance of understanding the values which the individual has and the judgements they make can not be over emphasised. Independence is individually defined. This is illustrated by another participant, Mrs Gaynor, who described herself as 'fully independent'. Prior to attending the day hospital she had not been out of her house for two years. A home-help brought her shopping, and collected her pension, and frozen meals were delivered daily. She heated these herself. So long as she was able to do this, she considered herself independent. She also felt she had some control, in that she was living in her own home. She both expected and accepted that certain tasks, such as shopping, would be carried out as she felt some decline in her physical activity was an inevitable part of the ageing process:

*Well, you expect it at my age, of course. I don't think I do bad, actually ... I'm very unsteady on my feet and I can't walk far now*

(44, 4,23)

A widow, with one son who lived abroad, she lived in a terraced house in a quiet street, about hundred metres from a busy main road. She could not manage to climb the stairs and so lived only in the downstairs part of the house: the lounge at the front of the house had been converted to a bedroom, the dining room at the back, had become the lounge. Mrs Gaynor's eye sight had deteriorated so much that she was unable to read for long periods of time, and she said she did not like watching television. She appeared poised, comfortable and relaxed. When asked to describe a typical 'day in her life' she described it as '*quite quiet really*', saying she had little to occupy herself, and felt there was little in turn to motivate herself. Many of the household tasks which had previously filled at least part of her day had now been taken over by a home-help from the social services, perhaps hindering rather than facilitating independence:

*Apart from heating my meal, that's it really. Quite quiet really is how I would describe me, well my life really! ... I'm alright and that, but apart from Dorothy {home help} I see nobody. (pauses). And I miss that (pauses). You get used to it, mind, and that (pauses as time goes on). And I've never been one for idle chat, I quite like me own company and I certainly like my independence. I like getting my meal - it's the highlight of the day*

(44, 7,18)

### ***Empowered individuals: relationships with others***

Mrs Brown lived with her daughter and her family, but this was in Mrs Brown's own house. She was unable to walk far and was confined to a chair, unless someone helped her up. She found it difficult to decide whether she was 'independent' or not - again preferring to say that her daughter 'helped' her with various things:

*Well, with what I need, it's just a case of somebody being here. I can't answer the phone because its in the hall, and if I have to take a message*



*the girls have usually taken the pens - they don't mean to but they like to draw and that and they move the pens. It's just being around. It's more helping, like she helps the kids or David (husband)*

(28; 5; 15)

Here she makes the distinction that the whole family is inter-dependent and rely on each other for help with all sorts of tasks, a positive experience of inter-dependence.

Mrs Brown had previously lived with her other daughter following a hospital stay, but this arrangement had not worked out as the house was cramped, her daughter and son-in-law were out at work all day and she said her grandsons' friends were very noisy. She described how she was left on her own for long periods of time each day, in an area where she had no friends, and subsequently began 'to go downhill':

*I wasn't failing as such, but I was very down, because Pam went out to work, and so did Geoff.....I'd always liked a bit knitting and a bit sewing, but I didn't feel up to it, which is how I knew I was so worried about the house and leaving it empty for so long ....so I decided I'd better go back home, but I didn't want to go back on my own*

(28; 3; 8)

As it happened, her other daughter's family and her moved into the house with her, as her husband had just been made redundant and they could no longer afford the mortgage repayments, and so this arrangement suited everyone. This account again illustrates how people have different views of being independent depending on their own personal circumstances. For Mrs Brown, being 'independent' in terms of living alone in her own home, was something she neither desired, nor aspired to. The years after her husband died were extremely lonely for her, which she felt compounded her grief. Her ideal situation now was to live with her family:

*I don't use all the rooms now. I just live in here now (back room), with it being cold, it seemed the most sensible thing to do, and that way I don't have to heat all the other rooms downstairs, just for no-one to be in them.*



*I'm very determined (to stay), this is my house and home, it's got all my memories ... my friends are down the road and that's how it's going to be until I die*

(28; 5; 16)

So, while there was a desire to remain independent, this was defined and organised on individual terms, which changed along with events. She acknowledged that she probably needed help with some aspects of daily living, but as this was provided in the context of her own home, and by family members, she accepted this:

*I manage okay, really, I mean if they weren't here, I might not cope so well, if I was on my own, not without some help of sorts, but they are here. I like my privacy mind you, and they know that when I shut the door they don't come in, the bairns, but we all manage very well... It's good with me because I've still got the spirit see, the spirits still there, whereas with a lot of people like me [older] you'll find they let go.*

(28;12;8)

This arrangement provided her with a sense of security and also, crucially, with a sense of control. Without talking to the other family members it is difficult to identify the exact process of how this occurred. But it seemed that decisions about care and the maintenance of this participant's independence very much occurred through a process of negotiation. Participants like her seemed to be consulted about everything that concerned them, from new clothing to more major decisions such as moving house or home alterations. This fostered a sense of belonging and also a sense of equality. Family members seemed to restrain themselves from 'doing too much' for their relatives, as participants had made it explicitly clear that their independence was important to them and they would not compromise it. Occasionally, however, the price of maintaining these relationships based on negotiation was worry, frustration and self-doubt:

*If I don't keep going, if I don't keep up with it, it'll all get on top of me. I know that it's like if I stop for too long, I'll stiffen up and if I sit for too long you just stiffen up and you can't move. It scares you if I was honest ... And think it's more ... it's better if I'm left to get on with things*

(28; 8;7)

*I can't read, I can't sew, I'd just be left sitting, and I never like watching television. At least this way I can do some cleaning, I do the veg and look after the kids when they come in, you know, I feel involved. But I see her look sometimes ...and she knows ... I can't do as much*

(28;5;9)

They talked of remaining independent as 'the right course of action'. This seemed to be linked to the public account of 'not being a burden'. At another level, they worried about the risks associated with independence and whether or not they should be accepting help when it was offered, even if they did not perceive they needed it:

*I've always been so independent. That's what I'm like. I'd feel like a caged bird if I couldn't do what I've always been used to. It'd kill me, it would*

(1;1;3)

*I get very tired these days. But I want to stay fit and healthy and you can't do that by sitting around all day. You're no good to anybody then*

(1;3;7)

Ironically, participants felt that promoting their independence was associated with risk, and protection from harm was associated with dependence. Participants who lived with their children could tell that they worried about them, and were fearful that they had a fall or hurt themselves when they were out of the house. This was very upsetting for them as it made them feel a 'burden' and a 'responsibility':

*I know she spends a lot of time worrying herself sick. I can see it, her lips go all tight as if she's dying to say something but daren't say them. I get angry, it's upsetting because there's no need*

(28; 9;17)

A fear of the implications of upsetting close family then, often limited activities and in time seemed to be a factor in ultimately lowering participants confidence and self esteem.



Where decisions needed to be made about care/ help, these participants negotiated what help they needed, by a limited agreement between themselves and family and friends, over a range of activities that someone would carry out for them on a routine basis. Shopping was the most usual activity. A few of these participants did their own shopping. The participants who did not do the shopping were always involved in 'doing the list', a contribution which they valued:

*I can't walk any distance, my knees let me down, but I say what I want and we do the list together, a little stock of what we've run out of or what's getting low. We've always done that*

(28;6;6)

New issues about care/help were raised in one of three ways: occasionally a participant recounted how they would raise an issue in a general way or ask for something specific to be done. More frequently, it seems, relatives or friends made suggestions. But their sense of independence was also maintained by the fact that they felt respected by their families, and that families knew that when they asked for help then they really needed it. This, they felt, had been a contributory factor in helping them accept any 'physical' effects of ageing;

*there is the side of things when I do some things now, I pay for it after. Like before, I used to clean right though on a Monday, I could do every room in the house, but the back room and the out-house. Top to bottom, it took me all day. Well, now I couldn't do that see. Just last week, what was I doing? Oh, aye, that's right, yes, I was trying to get at the hanging basket outside the front door there, you'll see it when you go out, had twizzled round in the wind, and I got the ladders and got up to undo it. Well, there was a time I thought nothing of it, but it put me back days. I was good for nothing until the weekend. Three days it took me and I was worn out. So I know that it makes sense to ask one of the children to get up for Granny*

(1;7;4)

*I don't like struggling, but I don't like to think I'm being taken over.*

(28;1;15)



When this sense of respect was challenged, so too was participants sense of control. Significantly, this usually occurred when 'others' or 'outsiders' determined that an individual's health had deteriorated. At times, participants had the sense that their family had gone against their wishes, and found this frustrating and disempowering. These events seemed quite rare, but were usually recounted with regard to calling a doctor, when they were unwell and the family had clearly felt, in such circumstances, they reserved the right to act, without consulting participants, as they perceived it was in the participants best interests:

*They asked the doctor to come round, without my knowing. He said he just popped in, but I know they called him to come out*

(1;15;25)

*Vera called the doctor round - she said after that she'd done it. I think it's with my condition, they like to be careful, but I wish they'd ask me*

(28;12;3)

A perceived change in health, seemed to legitimise others taking a more paternalistic attitude, raising some questions about the equilibrium of the equality of the relationship.

### ***Dependency as a positive outcome***

The concept and meaning of dependency has been widely debated (Van Den Heuvel, 1976; Walker, 1982; Johnson, 1986; Arber and Ginn, 1991; Dant, 1988j).

Although 'maximising independence' is seen as a central goal and an ideal outcome for many rehabilitation services, this assumption is in itself value-laden, and may actually contradict what some people want. Some people may actually want or expect services and care to be carried out for them (Qureshi, 1991).

They may want to feel 'dependent', as they define it. Two of the female participants, Mrs Lorrimer and Mrs Harriman, lived with their daughters, and a

further two Mrs Hatfield and Mrs Royale lived alone, but close to their daughters, who provided most of their care. Three of the daughters were married, one was widowed, and all had children of their own. The participants were in their late seventies or early eighties, the daughters were all in their late fifties or early sixties. From the accounts it was clear that these four participants had always encouraged their children to help them with the housework, the shopping and the cooking which they had viewed as an integral part of their children's development. A knowledge of their life biography gave the account context which was important in interpreting events and behaviour (Phillipson, 1991). From an early age, the participant's children had been deemed responsible and frequently looked after siblings while their mother worked. From an early age, these mothers had had a very close relationship with their children:

*We ran a fish and chip shop, just me and Moira after Billy died.... We didn't have any option, but I taught them how to help out, with the deliveries and that and they were serving in the shop when they were ten or twelve.*

(24; 28;30)

The children had grown-up in a situation where they had always helped and supported their mothers with daily tasks of routine living.

Mrs Lorimer, described how when she and her husband retired, they had moved north to be nearer their daughter and her family. After her husband had died, she again moved near her daughter, selling her own house. She felt unsettled in the house, however, and one day, almost on impulse, bought a house on the coast, some miles away, despite protests from her family that she was making a mistake. She described how, for a time, she had liked it there, but began to visit her family more and more, and for greater lengths of time. She found it difficult to make friends, mainly because the area in which the bungalow was built consisted of holiday cottages and so residents were seasonal. In the winter, the

village was inhospitable, which left her virtually isolated and feeling like a prisoner in her own home. Throughout the winter and the spring, strong coastal winds kept her from venturing out of the bungalow for fear of being blown over. She had long since lost many of her long-standing friendships, and telephone contacts and letter writing had become fairly insignificant activities. Litwin suggests that older people who participate less with friends begin to focus attention on significant others, with the expectation of receiving emotional and financial support (Litwin and Auslander, 1990). In the light of this ever-restricting social world, she increasingly relied on her daughter for company and contact:

*It was getting too much for me, all the worry and the travelling. It was so cold in the winter, and I worried about having enough in, and sometimes you get like you can't be bothered. Anyhow, I decided I'd move back for good*

(22;2;12)

There appears to have been little negotiation between Mrs Lorimer and her daughter and family. Mrs Lorimer appeared to increasingly expect more care, including personal care, and saw this as an extension of what she had provided for her daughter when she was younger. Comments about personal care commonly involved help with getting in and out of the bath and washing hair. When Mrs Lorimer was interviewed she was sitting in the lounge, fully dressed, but apparently she spent most days in bed. Her increased dependency on her daughter she felt stemmed from a fall some months previously. The fall had severely shocked her and fear of further falls had changed her behaviour. Up until the fall she had been a self-sufficient woman who valued her independence and was willing to move to live alone over 150 miles from her family. However, the fall appeared to have alerted her to her own perceived physical vulnerability and she had become increasingly fearful of more serious injury and the



possibility that her daughter might leave her. She chose and justified her dependence:

*I had a fall back there, never really got over it, and I can't get up now, I'm in bed, I can't get out.*

(22; 17;4)

Three of the other participants had clearly had similar relationships with their daughters, where they had always been dominant in the relationship, and were empowered because, whatever their circumstances, they were largely in control. This had been extended from childhood into later adult life, and now there appeared to be an increase in the participant's expectations of and demands for care, often coinciding with the daughters retirement and their subsequent perceived greater availability:

*Pam comes down and sees to me. She comes every day now that she's finished work*

(11;41;40)

*I wasn't too bad during the day, but I wasn't good at night, and so now my daughter comes and gets me into bed and that. She's got more time now that she's not working*

(11;25;34)

Eichenbaum and Orbach (1983) note that mothers who find their daughters potential for independence and autonomy threatening, often use signs of their own vulnerability to encourage daughters to begin to look after them. These participants seemed to direct the way that their care was organised and managed by their daughters. There had been changes over time in the way that decisions regarding care were made, but overall the balance of power appeared to remain with the participants. Throughout one interview, Mrs Harriman gave frequent demands to her daughter, and hammered on the lounge wall with a walking stick to get her daughter's attention. Participants appeared to be using

their 'need for care' as a way of exerting control and power over those caring for them, a pattern of behaviour which had developed and continued over the life-cycle. Any offer of help from the statutory services or outside their family was viewed as an unwelcome intrusion. It was unclear exactly why they were so worried about outside help, but possible reasons include that they felt that the situation would be unstable and beyond their control, or that ultimately, they may be placed in a home, against their wishes:

*I was offered meals-on-wheels, but I don't want meals-on-wheels. Well they delivered them, on a trial, but I didn't eat them. They were just being wasted. The next thing: would I have a home help? I told them no, I would have no such thing. [was that because of the type of services she was being offered?]. No, no, I didn't want any one else in, my daughter does for me, she can do it, I didn't want it and we can manage with what we've got*

(24;22;22)

Because of this antipathy towards the statutory services, people often were unaware of useful items of equipment that they could borrow from the health authority or social services department and as a result, carers often went to considerable expense to buy equipment such as bath seats, special chairs etc.

Interestingly, contrary to definitions of dependency which associate dependency with powerlessness (Walker, 1982), these relationships highlighted the ways that participants could be both powerful and physically dependent, and carers could be 'independent' and powerless. In part, participants were able to define themselves as dependent because they had established a position of power which carers accepted. Over time, as a carers range of options narrowed, the scope for changing the balance of power within the relationship also diminished. Financial and structural dependency on participants, meant that some carers could not easily walk away from these relationships, even if they wished to.

Choice and control were significant factors even in the context of severe physical limitations. Mrs Webb and Mrs Cliff had seen gradual changes to the way in which the household was run and decisions were made as to the effects of their illness. Although on the face of it, these participants were receiving the same type of care activities as other participants, the physical nature of care seemed to figure more prominently in this group than with other groups. This group included more frail participants; participants were physically disabled, for example, following a stroke, or heart failure. Mrs Lynch was in the early stages of dementia, and was frequently confused about her whereabouts and had problems remembering how to do simple tasks. She could not communicate advance warnings when in danger of falling, or being hurt, or being hungry or when wanting to go to the toilet. In these ways, she seemed to have been robbed of her ability to sustain and initiate independent activity, by the nature of her disability. Through these physical and/or mental changes, participants had lost the ability to express their identity and relied on their partners for most physical functions. However, for some there appeared to be a degree of partnership in the acquisition of these skills.

*I'd sit and tell him what to do. It was a combination of lists and questions. I'd try and write things down as well, but it was difficult because I can't hold anything see, and it's so hard trying with your other hand. We got a system going eventually. After a time I'd have to say less and less and we just learned really. If you've got decent back-up it's less of a problem. I'm fortunate in that respect.*

(46, 4;8)

*I advise him as he goes along. We've always done it that way. We sort of work as a team. I think it makes me feel involved*

(10;3;4)

This illustrates how, while to outsiders, a person may appear hugely disadvantaged and incapable of performing tasks for themselves, they may still retain a sense of control over their situation and a sense of belonging and being



involved, which contributes to their sense of well-being. Decisions were on the whole taken jointly participants participated in some way in their own care:

*We seem to have become closer through it all really, which is quite surprising really. We talk more than we did before and we sort of try and solve problems together*

(39;5;4)

### **Summary**

These individuals demonstrated how, even in the face of considerable impairment from chronic illness, they retained a sense of control over their circumstances and importantly, change in their circumstances or in their condition. A number of factors were identified as contributing to this, including personality, their home circumstances and life biography. The group comprised of a range of ages, marital status, both genders and stages of chronic illness. These differences need further study. The reason they were labelled 'empowered' was because they were *conscious* of the need to manage change and recognised the value of being involved. This was not always an easy process to maintain, but they considered it important and felt it was imperative for them to retain control, if they were to continue to have a voice in future decisions concerning them, in the face of discrimination because they were 'old'. Equally, they were conscious of the institutionalised ageism in society, and actively developed strategies to manage the effects from both their family and friends, and in the wider community, with varying degrees of success.

### **Reluctant collaborators**

A group of participants were characterised as being frustrated in any attempts to influence and control decisions, but reluctantly went along with them as they perceived there were few alternative routes available to them. The term was coined by Waterworth and Luker (1990) to describe a group of patients who did

not want to be involved in decisions concerning their care, but felt pressurised to participate. A slightly different emphasis is put on the term in this study, and more attention is given to the reasons why people might be seen to be 'reluctant collaborators'. This group's views certainly seemed the 'most common' amongst older people contacted for the study. Again, there was a range of ages (68- 86) and socio-economic groupings in this group. These participants again illustrated huge diversity in terms of adaptation to the effects of chronic illness and in their own meaning of independence. A core theme throughout the accounts is institutionalised ageism and the context in which older people define quality of life. Therefore, in this section, the core domains are discussed to illustrate what the predominant themes and 'feeling' was from the participants accounts.

***Reluctant collaborators: negotiating control***

The emphasis on activities of daily living very much reflects the professional view of what are considered to be important areas on which to measure the success of rehabilitation and with which to measure an individual's independence. Mrs Jones felt that her condition had deteriorated. She had rheumatoid arthritis which meant that she suffered a great deal of pain, and she felt it was this that made her feel depressed. As Williams and Woods (1988) in their exploration of the negotiation of autonomy in rheumatoid arthritis state:

in the presence of pain and stiffness, people are turned in on themselves and become pre-occupied very often pain becomes the defining feature of the individuals private world, silently controlling activities and relationships while at the same time remaining invisible to other people and eluding the vocabulary of ordinary language

(Williams and Woods, 1988, p129)

She said that she remained in bed for most of the day. She saw no-one, apart from a home-help who came in once a day. She listened to the radio occasionally and tried to read but could not concentrate because she was in pain.

At the time of the interview, she was upset as her home-help had told her the previous day that 'if she only tried she would be able to get out of bed'. She had told Mrs Jones that she ought to take responsibility for her domestic environment and keep busy:

*she doesn't see it. She's never had pain, oh people have the odd pain, a headaches, you know, but not like this. This is, it's you can't describe it, and I wouldn't wish it on my worse enemy, I wouldn't*

(14;15;4)

Without interviewing the home-help, it is difficult to give her comments context: they may have been intended to galvanise Mrs Jones into activity which the home-help genuinely perceived was better than staying in bed. For Mrs Jones, the beginning of care was defined in terms of when she had had to withdraw from domestic responsibilities and this took on symbolic meaning. Although eventually she needed help with more personal care, 'care' and its beginning was associated with a change in role. Care meant 'having things done' because she was perceived to be no longer capable of doing them herself, which she found frustrating:

*It's been gradual. Up to about four years ago, I could do a bit, I cooked and all that sort of thing. It was funny in a way what I could and couldn't do. I could push the Hoover but I couldn't dust. When I say that to people they think I've got it the wrong way round, and they say to me no, you mean you could dust, but not Hoover*

(14;15;4)

This example illustrates how other people, 'outsiders', deem to know what is best for the individual, from what they should be able to do and doing, to what they are saying (Merton, 1972). The social services had intervened following a hospital out-patient visit and Mrs Jones now had a home-help who came in and cooked her a meal at lunch time and left her a sandwich for her tea. This is a common-enough occurrence, but had been a difficult adjustment for Mrs Jones.



She had always enjoyed cooking and enjoyed being in the kitchen. She had worked for ten years as a cook at a local primary school and cooking had always been an integral part of family life. From an outsiders point of view, although she lived alone, she was dependent upon home care and social services for support. However, from Mrs Jones accounts, there seems to have been little meaningful negotiation in terms of changes to her life-style, although clearly she was consulted, and meant that the new role and the new relationship between this participant and the home-help was forced. Mrs Jones felt she had had no time to adjust to the new situation. There seems to have been no attempt in Mrs Jones case to consider her personal needs and her personhood. An external source had decided on a perception of risk and hazard - i.e. that Mrs Jones' arthritis in her hands made it impossible for her to be considered safe in the kitchen and therefore she needed a certain level of support. The needs had to fit the existing service. For example, Mrs Jones found it hard to peel vegetables or to fill and lift a pan of water. However, she could turn the cooker ring on and off. She recounted how she had asked if it would be possible for the home-help to put some peeled vegetables in a pan and then she would boil them when she felt ready to eat. It would seem that this was perceived to be risky and was not possible, and after being refused the first time, Mrs Jones had not asked any more as she felt it would be a pointless exercise. She had been forced to adapt to the new situation, but her perception of risk clearly differed from the paternalistic views of professionals involved, and there appears to have been limited negotiation or attempts to decide on a compromise. Because of different perceptions of risk and inflexible service provision, far from feeling more confident and independent, Mrs Jones was left feeling disempowered and out of control. This example demonstrates how an approach which focuses on a medical condition and basic activities of daily living is rather narrow and

incomplete, as it lacks context. Mrs Jones acknowledged that she had a serious problem with her arthritis, in that the pain in her hands as a result of arthritis was getting worse and that her joints were stiffening. She was unable to comfortably do many of the things she had previously taken for granted. She welcomed some help with these activities. However, while her condition had deteriorated, this had been gradual and Mrs Jones felt that she had adjusted and accepted this. She was also aware of the temporal nature of her condition (arthritis) and that on some days she was 'better than others'. Her desired outcome from health care services, she said, was unequivocally pain control. She felt she was realistic in what she could expect and that there was a degree of success in managing this:

*there are so many tablets now that I take, mainly to help ease the pain in my fingers and here. They're very good, actually - I don't expect miracles, but if they can keep it at bay, that's something*

(14; 4;17)

However, her sense of choice were compromised by her enforced dependence on social and health services. Again, her sense of lack of control contributed to her feeling that the only future she could expect was one of deterioration and increased dependency, which clearly depressed her. Despite the fact that at present she felt that the pain was controlled, ultimately she saw only a negative outcome as possible. She explained any changes in her situation as due to her own illness, she blamed her illness and her age, supporting the theories that ageism and 'blaming the individual' become a self-fulfilling prophecy. From Mrs Jones perspective, the 'success' of the pain relief, a positive outcome of treatment for her, was dimmed by the fact that overall, she felt that her quality of life was diminishing due to this threatened sense of independence.

**Reluctant collaborators: decisions about care**

The hospital environment was frequently mentioned as an atmosphere which hindered greater participation in care-planning, because of a feeling of insecurity and powerlessness. This again hindered involvement in the decision making process. Given that this was the case, participants were then asked if they would feel happier in their own home, on their own territory. Participants did not know if this would help. They found it easier to discuss services rather than specific treatment interventions. It is suggested that when statutory support is offered, it tends to replace rather than complement carers' expertise (Brown and Smith, 1993). In this study, too, the services that were on offer were those designed to replace the various activities that participants routinely carried out. However, the level at which the services were offered makes the possibility of such services actually replacing the level of care given by the partners unlikely. One participant said:

*it all boils down to: do you trust them? [what do you mean?]. To turn up on time, and when you need them, to do things properly, not just any old how to get the job done, to tell you what's your entitlement, it's all these things that would make a difference, and that's just for basics*

(13;36;17)

*You know, I've noticed that everyone who comes here comes for a purpose - I mean they come to do something, or to get something, no-one comes just to sit down and chat, no one just comes*

(7;17;2)

One participant described how her home-help temporarily had decided to reorganise the house so that things could be run more efficiently:

*That's what she told me, so she changed the cupboards round, moved my three piece round....oh, and she paid the bills differently. It was all very muddling*

(6;26;9)



This challenged her feeling of control, but she felt unable to say anything as she felt she ought to be grateful for the help she was receiving at one level, and because of a fear of retribution she was unlikely to pursue any lines of complaint. This mirrored themes in the public accounts.

It was in the accounts from the most vulnerable individuals that the public and private accounts blurred. Many felt tired of 'fighting': tired of responsibility they felt to ill and ill equipped to cope with, tired of having to make decisions, and live with fear of the consequences and tired of feeling alone. They therefore often agreed to suggestions or made decisions, which they perceived would be in their best interests, in that they caused the least hassle and disruption to others and they felt that they would benefit from this.

Many older people in rehabilitation settings are forced to make decisions about their lives, at a time when they feel uniquely dependent. Participants who had spent periods of time in hospital had become quickly institutionalised to the extent that they had been reluctant to perform any activities of daily living alone without a member of staff, usually a nurse, present.

They talked of the fact that nurses were aggressive and annoyed if they performed certain tasks alone, and then were equally annoyed if they asked for assistance with other tasks. This presented confusing messages to individuals in unfamiliar and uncertain surroundings. The wish to please and conform became very strong in terms of small personal tasks, and this seemed to translate to more important potentially life-changing decisions, such as moving in to long stay care.

In such circumstances, attempts to discuss outcome with these individuals were problematic in that these individuals relied heavily on their public accounts. They

were firm in their opinions, and superficially it would appear that they were very clear and certain about what they desired:

*I want to move to the Rose Top (nursing home). I'll be better there where there is someone on hand to look after me. I need looking after*

(13;44;6)

They also appeared to be very clear about what they could expect in terms of health care outcomes:

*Look (pulls skirt up). Look at them. They'll never get any better, the nurse told me I'll never be able to walk again*

(13;34;17)

Once they had made such a decision, they began to tell friends and family, and usually received a positive response which they welcomed:

*I told our \*\*\*\*\* when she came yesterday and she was pleased and she said '\*\*\*, you've made the right decision', she said. I think it's the right decision, don't you?*

(13;45;6)

This participant sought approval from others. She seemed to have made a decision, and when she informed others of this decision, she anticipated, even expected approval for her decision. This was because she assumed that what she was saying was what her friends and family wanted to hear. She wanted to conform, to present the public account, even if these decisions contradicted her private thoughts. For a time, participants seemed actually to convince themselves that this is what *they* wanted, and seemed to gain a sense of empowerment from making such what they perceived would be regarded as a positive decision. However, this feeling usually seemed temporary, and invariably as the interviews progressed, private views emerged which either contradicted what they had been saying, or which highlighted real uncertainties and fears which underlay their outward positive demeanour:

*It's not what I really want, you know. But there'll be less fuss that way and it'll be better for everyone*

(13;47;8)

*I had Norman yesterday, for a visit, and I told him, and she said, 'yes, you're not getting any younger Gwen, you need to think ahead, while you're still able to think for yourself', you know.*

(8; 21;23)

These participants were again influenced by institutionalised ageism, and the ageist attitudes of their friends and family, and of the health care professionals they came into contact with. This latter participant's friend had assumed that the future would bring increased incapacity and dementia. Faced with such negative attitudes, and with such potential disapproval should they decide to go against what other felt was 'right' for them, they felt even more vulnerable and alone, and clung to an outcome which they felt would please others, and to which they resigned themselves to having to adapt to. So these participants were termed 'reluctant collaborators' in that they agreed to conform to the public account, while privately holding very different views, and desired outcomes.

These participants were more likely to say they felt depressed, anxious or uncertain about the future, and it was difficult for most to perceive anything other than negative outcomes:

*The doctor said that I'll never be any different, I'll never be any better, I'll only get worse. I'm 86 ... I'll be dead soon*

(31; 6;19)

### ***Reluctant collaborators: relationship with others***

Some people felt that their carers could not understand that they did not welcome the opportunity for everything to be done for them and be looked after:

*She's getting intent on doing more and more. She insists I'm deaf and I have to go to the doctor for this, and the doctor for that. She's booked me a hearing test for next Monday or is it Monday week...But I don't want a hearing aid, I manage fine with the telly turned up*



*I feel as if sometimes she likes telling me what to do and I don't like it one bit. It gets me very annoyed. I'm not complaining but sometimes it does get a bit heavy and I tend to loose my temper. I know I shouldn't but it's difficult. But I don't want to fall out with her, I want her to help me, but she's so pushy.*

(9; 15;7)

This participant illustrated how 'outsiders' (Merton, 1972) decide what is best and try to determine events. It was clearly '*not acceptable*' for the television to be turned up loud, '*not normal*' and so the stereotypical idea of 'all older people have a hearing aid' comes into place. Such ideas are so fixed, that it becomes difficult to be flexible to accommodate individuals' needs and circumstances, develop fresh approaches to a situation; to incorporate how an individual may adapt to their situation. This participant's hearing difficulty was clearly more a problem for others round her than for herself - she did not perceive it as a problem or prioritise it as something that needed any kind of professional intervention. She judged that her hearing was only slightly worse than it had been a few years previously. She said that she had difficulty hearing in crowds, but it presented no other handicap for her and could hold conversations with people around her. On returning to visit her three weeks later, however, she had kept the appointment for the hearing test that her daughter had arranged for her and a hearing aid was on order for her. It seemed likely that over time, the situation may actually become less conflict ridden, as this participant became less able and less willing to protest and more likely to conform to others wishes.

It very quickly became apparent that there were major differences between how participants were talking about their health and health care, and what domains were important to them, and the way that professionals have traditionally considered these issues. There was also an emphasis in participant accounts on process issues. These differences eventually led to a concentration in the

analysis on these. There was a feeling that the statutory services could not provide the same type of care as families provided:

*I think that no-one could give me what my daughter gives me. You know, no matter how good a nurse you are or helper you are unless (pauses) unless there is a tie of friendship, it's not the same.*

(2;25;29)

*It's about caring about, not just for. I mean you could live up to your ears in it, as long as there's someone coming in who thinks a little bit of you*

(31;4;18)

Their experience of health and social services differed, and some lost faith if this experience had been negative:

*I was having trouble with my waterworks, I had to go (to the toilet) an awful lot. I could only last, oh, an hour at tops. I explained about this and everyone said to me "Age". But I'd never had it before.. and it wasn't age, I had an infection in my water. It's as if when you get old everything that's wrong with you is down to age*

(6;33;4)

This contrasted with the public accounts when people felt that services had to be limited because of the growing number of older people and the strain this put on scarce resources:

*As I said, there's not enough and when you get to my age - I'm 86 in January - you're bound to have troubles because I'm old. Me body can't do what it used to*

(31;7;3)

Participants had been to nursing or residential homes to visit a friend or relative and had not received very favourable impressions of them:

*I went to a home to visit me aunty when she was in - this is a few years back - and they seem to look after them you know, she said the meals were nice, and the girls were very kind, and that, but, well, there's no love, you know, do you know what I mean? You get the feeling that there's no love, and when it all boils down to it, well, you're just one of a number aren't you?.... You go in .... and they carry you out in a box.*

(7;16;33)



*I had an auntie that lived in a home and we used to go over...they are very nice some of them, I think it depends on who runs them, you know, you sometimes go into them and the smell, well you used to go in, and the smell just hit you. Ugh. I wouldn't want to go in one myself having seen that one, but you just don't know. I think it would be very upsetting, and I'll try my damndest not to but at the end of the day I've got Sylvie and the kids to think about and I know I might have to but it's right at the back,, I don't think about it.*

(2;17;8)

This again reflects the conscience that was in the public accounts, a sense of obligation not to worry or burden younger generations. It also illustrates the sense of inevitability that some people feel with regards to end-of-life-care, and the lack of control over decisions and lack of choice that they feel that they may have. However, a sense of control over future events and maintaining this for as long as possible was crucial. These participants very much felt that going into a nursing or residential home to live was the 'beginning of the end' and resisted all suggestions that this might happen. They had always been brought up and lived with the idea of self-sufficiency and self-determination and found satisfaction in achieving this.

### ***Marital relations***

Major differences emerged between single people and married, based on the development of their biography. Wives whose lives were deeply interconnected with their husbands lives (structurally, financially and emotionally) perceived themselves to have more courses of action. All of the spousal relationships had, in the period prior to retirement, been organised upon the traditional lines of responsibility: husbands went out to work, managed the financial affairs and household repairs and gave their wives housekeeping money. Wives carried out all of the childcare, and the household and domestic chores, and most often had some form of employment. There was some evidence that the conjugal roles adopted, in the main, conformed to the 'separated conjugal' type (Bott, 1971). That is, husbands and wives had a relatively large proportion of independent and



complementary activities and a relatively small proportion of joint activities. For this group, it was the nature of the participants' impairment that proved to be the most influential factor in determining the way in which care was managed and experienced. In the majority of cases, the end of work or beginning of retirement coincided with the onset of illness.

Amongst the group of wives who were cared for by their husbands, there seemed to have been no opportunity of role re-negotiation at the beginning of care.

According to these participants, 'roles' evolved through an instinctive response to the imperative of need. The participants felt they were incapacitated and their husbands were not, and if the husband did not 'take control' then no-one else would. Some felt that if it had been the case whereby it was their husbands who had been physically prevented from maintaining an active role in the household, then they would have resisted the idea of their wives running the household.

However, many of the woman participants were not in a position to express resentment or frustration at no longer having a clearly defined role in the household, but accepted the position:

*Definitely you're a changed person, you've got to be, you know you suddenly realise that the whole thing relies on them, you realise that they're the main one, the head of the household, sort of thing. I rely on him totally. You wake up one morning to find your whole way of life, down to the smallest detail has changed. Even little things like I was always the one to go to bed last, and I used to watch telly and read and that. It's all changed. And that comes over you.*

(31;1,5)

*He has the whole say in everything, not because that's what I want, because honest to God I never wanted this, but because I physically **can not** (her emphasis) do anything. I rely on him for everything, totally, he decides everything*

(3, 5,17)

*Well, I mean I'm so dependent on him. I mean I was very independent before, I was dependent on him for like arranging things and that and doing things. But you have no choice about it. It's not something that you*

*have any control over, you just accept it and get on with it and I suppose that goes for him and look how things turn out. When things like this happen choice doesn't come into it, you just have to get on with it.*

(3; 31;11)

There were, then, differences in how different people conceptualised independence. The accounts clearly showed that mobility and physical functioning were considered to be important domains to participants, in that decreased levels of mobility and physical functioning could impact on a person's ability to carry out certain tasks and interact with others. However, individuals do not function in isolation; all human life is interconnected, and the concept of independence was defined very differently by different participants, depending on their subjective interpretation of events and circumstances. Accounts comprised complex narrative reconstructions of the persons life and in explaining their life story, participants drew on aspects of their relationship with their friends and family over the life-cycle.

The relationships and circumstances described in this section show how older people may encourage being dependent as ways of controlling the care they receive, from family members. None of these people were heavily physically incapacitated. 'Care' involved household tasks such as cooking, cleaning, washing and some personal care. These participants did not fit in with the stereotypical view of being dependent. Dant (1988) defines dependency as a complex exploitative manoeuvre by someone from a position of weakness, in transaction with another, or others, considered to be in a stronger position. This definition is problematic. The idea of these participants encouraging their own dependency goes against the view that older people regard the prospect of becoming dependent on others with some trepidation (Wenger, 1984; Qureshi and Walker, 1989). Braithwaite (1990) states that 'dependency in adulthood threatens cherished values of self-respect and human dignity' (Braithwaite, 1990). It could be construed that these participants had abandoned their self-



respect and dignity in the face of greater concerns. It is possible, then, that for some people the insecurity of old age and fear of illness and dying may be so acute as to push notions of self-respect and dignity into the background.

These ideas militate against assuming that maximising independence is necessarily the desired outcome, and some people appear to gain most satisfaction and a sense of security from actually becoming more *dependent* on others. This dependency appears to stem from an insecurity about illness and old age, and was legitimised by participants feelings of reciprocity, also in the public accounts, a pattern that had developed over the life-cycle. In these cases statutory support was refused; this seemed to be associated with a threat to controlling their situation.

Clearly the aspects of independence which are highlighted in the social model, are very much included in how older people conceptualise independence. A definition of independence which focuses solely on the individual being able to carry out various tasks is incomplete and partial. Similarly, a model which focuses on the individual, is again partial as this fails to take into account the extremely complex and changing relationships of which older people have been and are continually part of over the life cycle, and the temporal nature of chronic illness. Society places great value on what is considered to be 'normal' (Morris, 1993). There are a variety of ways to describe the word 'normal'. On the one hand, it could be a relatively value-free word, meaning what is common or usual. In this particular case, to be different from normal would not necessarily provoke prejudice.

'Normal implies that which is average within any social structure. Those who do not conform to what is average in terms of appearance, function, behaviour or belief are no longer 'normal'.....there was a renowned Cambridge don who hated being obliged to respond to aimless chat on long air journeys. So, before embarking he would wind a piece of string around one ear and place it in the side of his mouth. This simple device



ensured that only the air hostess would dare address him. This may seem simply an amusing anecdote but what it tells us of human nature is infinitely instructive. The gulf between what is regarded as normal or abnormal is as small as what you choose to make of a piece of string'

(Morris, 1993)

## **Integration, not isolation**

A dominant theme which ran through all the accounts, and crossed boundaries of age and gender, was a need to feel socially integrated and not isolated. This was identified as the main area of their life in which people would like to see change. This was both on an individual level of having company and people to talk to, and also on a wider societal level of being fully integrated into a local community.

## **Family and Friends**

Ware (1987) describes social function as social contacts and activities, such as visits with friends and relatives and social ties, or friends and relatives that can be counted upon for social support. Some participants felt that they had lost friendships as a result of *their illness* and blamed themselves for this. Illness, they felt, was an inevitable consequence of growing older. However, there were differences in the various explanations as to why this had occurred. These included a lack of moral responsibility, a lack of empathy, selfishness and a perceived inability of others to cope with illness. Some people thought they might be to blame for not maintaining the reciprocal nature of friendship:

*Not everybody can cope with it. I think that's why they've stopped coming. I don't think they can cope with it. I just hope it never happens to them*

(6;3;19)

Participants focused on the personal effect that illness had had on the marital relationship. Here there were gender differences. Husbands who were the

actual participants (and therefore the person being interviewed) interpreted their situation by viewing the fact that they received more care from their wives as a continuation of earlier roles and responsibilities, in that greater physical tasks associated with care were an extension of their wife's skills acquired over the life cycle as mother and wife. These participants who had also cared for their wives, viewed the acquisition of these skills as something to be proud of, and found caring a rewarding experience.

## Community involvement

Parker (1993;36) suggests, in the context of caring, that belonging to a church or a particular faith provides opportunities for social contacts. She also suggests that it allows for the suspension and realignment of the expectations of reciprocity and mutual exchange on which friendship and neighbouring usually depend. However, several participants who had always attended church found it difficult to keep up their religious commitments. This seemed to be due to difficulties in formulating suitable arrangements for transport:

*I'd like to go (to church) but you know you can't get [what do you mean?]  
there's no one to take you, I need a lift to get there and there's no-one*  
(19; 16;19)

Mrs Barker did not feel her illness alone prevented her from actively participating in church activities. She physically could not walk the 500 metres up the hill to the church, nor could she drive her car because, due to the arthritis in her spine and knees, she found this too painful. She had sold her car six months ago. Her ability to get to the church on her own was therefore restricted due to her physical condition. However, she felt that the real barrier was not *her* limitations, but rather the limitations of her circle of friends, or rather these factors in combination. Without anyone to help her into a car and drive her to church, she felt unable to attend. I asked her if she had considered taking a taxi to church,



but being seen to be 'independent' in this respect was considered by this participant to have more negative repercussions than a positive result:

*I did think about getting Bysons [taxi company] out, yes, but... I'd just look daft wouldn't I? Getting a taxi not a few yards up the hill, and to be frank I don't think they'd come out cos it's just a few yards up the hill, just round the corner, and on a Sunday morning and all they'll not pretty thank me for getting them out for that fare after being out till all ours with people in town on a night time. And people are only funny you know, they're only funny and I tell you it wouldn't go down well with certain people I could mention, they'd think I was making a point at them [interviewer: wouldn't you be?]. Well, yes but not really, but then there would be whispers and that. I mean don't get me wrong they're nice people really but I don't think the taxi would work and there's nothing much left. I just can't get and that has to be the end of it it looks like.*

(19;18;4)

In this case, it seemed it was a combination of both Mrs Barker's restricted movement because of her arthritis, an environmental barrier and the attitudes and actions, or lack of action, from people in her community that actually 'handicapped' her.

We discussed her treatment at the day hospital. She did not feel that an improvement in her arthritis was a realistic outcome for her. She expected change as a result of the physiotherapy at the day hospital, attributing change as resulting from attending the day hospital. This was meaningful change to Mrs Barker. She felt that focussing on her arthritis at the day hospital was helpful *in the short term* in that the physiotherapy helped her movement inside the house. However, she felt that in the longer term the treatment would have little effect as her knees deteriorated and other environmental factors came into play:

*no not my knees, they won't get any better, in fact when the cold weather's back they get more painful, especially in here [points to knee]. I mean when I'm there I think it helps, you know, she's ever so good, and it feels bit better I think, and I quite enjoy going [day hospital], you know it gets me out*

(19; 26;17)



Four people interviewed had moved house - mainly because they felt they could no longer manage stairs to the bedroom, and so had agreed to move to 'a more suitable property'. All the new properties were either ground floor flats or a bungalow with wheelchair access:

*I moved here because I couldn't manage the stairs.*

(13; 7;18)

Although structurally more suitable, they were not always felt to be located in more congenial areas. In two cases, Mrs Kennedy and Mrs Black having turned down two choices of property, participants were forced to accept the third choice, or have their names either removed from the list, or moved to the back of it. Neither were happy with the area into which they had been asked to move. The ground floor flats were located on the edges of large 'problem' estates and both participants felt very vulnerable. Far from facilitating independence, this move had actually left Mrs Kennedy feeling 'worse off'. In terms of actual physical health, neither felt they had deteriorated over the last months since the move. However, Mrs Kennedy felt so depressed at her move that she was considering moving again, out of the area completely to be nearer her other daughter, who lived in the south of England:

*I don't think I'm any different. I still get very breathless, but that's my condition... I feel very down. Very depressed. I'm not near anyone I know, none of my friends are local, I'm trying to move down to be near Jean. I'll be better there - I can't get anywhere worse*

(13;16;10)

This illustrates how although in terms of crude physical and functional terms, the change of house may appear to have benefited Mrs Kennedy: a positive outcome. She now had no stairs to climb, which had proved a major barrier in her previous home, as she had fallen several times and suffered badly from

shortness of breath on exertion. She was also nearer to the local shopping precinct now and was deemed to be more 'independent':

*... they said (social workers) I'd be more independent, you know, with being nearer the shops and that*

(13;20;2)

From her perspective, however, the move had been a totally negative experience. Geographical isolation compounded her social and emotional isolation. Living on the outskirts of a large housing estate, *'in the middle of nowhere'*, she described how she barricaded herself in for fear of burglaries and other crimes, and felt she was constantly disturbed and intimidated by other inhabitants:

*Oh it's terrible. Terrible. You can't go out, you can't leave the house, it's not safe*

(13;20;19)

However, despite the problems she experienced, she felt unable to complain for fear of retribution. This reinforces the findings from the focus groups of participants feeling disempowered, with control resting firmly with professionals:

*I don't create because you never know when you're going to need somebody when you like me*

(13; 25;17)

The people in the study who viewed moving positively tended to be those who had greater financial resources to look for a suitable property in an area of *their* choice. Financial security was clearly a factor in giving people not just choice, but a sense of control and autonomy in their situation:

*I'd say we were comfortable yes, we've got a bit put by, you know and that and then when we sold the house in W\*\*\*\*\* we were able to look around until we found somewhere nice and that. We took our time looking, didn't we, it was, oh, well, it was the November when we moved*

*and we'd been looking since the January/February time, so nigh on a year, but we were in for Christmas*

(5;17;8)

These individuals were empowered by the fact that they were able to take their time in looking for a suitable place to live defined by their own criteria and were not beholden to others. They made decisions and had choices which meant they felt no obligation or influence from 'outsiders'. In the context of employment, power and status are derived from the possession of resources (Ward and Dale, 1992). This was clearly felt to be the case for some participants in this study.

### ***Finances***

All participants discussed finance at some point during the discussions, although the content and purpose of the discussion varied. Most participants had state pensions supplemented by occupational pensions and a private income from investments. Others relied solely on the state pension. Possession of savings was of great significance, in that people perceived it as the last thread and link to a past life and to facilitate hanging on to what independence they felt they had left. Control over finances seemed to be the key factor here, and having a regular income with which to be able to retain choice.

The public account of the future included the concept of 'going into a home'. This is what most participants stated that they expected to happen. Several participants worried that if they had to go into a residential or nursing home, that the "State", would take their assets and this would deny their family their inheritance:

*If I went in a home, the country would get the lot, wouldn't they, and my sons wouldn't get a penny, I don't want that*

(5; 17;6)



The private accounts, however, highlighted a great deal of diversity over ideas about the future and what would influence their fate. Maintaining a sense of control and a sense of power over affairs and events was clearly important. However, many seemed to perceive this as a constant struggle, indeed some participants spoke in the terminology of war, suggesting that they felt that this was particularly difficult. They talked of *'battling against the families wishes'*, or *'me against them'*. Others talked of *"arming themselves"* (7;36;18) and *"fighting on against the odds"* (8;33;24) or *"battling on"*:

*Since Bill died.. it's been hard. I know my daughter wants me to go into a home, I know that. She thinks I'd be better off in there, you know, get looked after and that, and then she wouldn't worry so. ..But I want to stay here and I'm going to battle on for a little while yet*

(14; 21;6)

*..you're always fighting something or somebody. It's hard enough fighting the cancer, without the family. [What do you mean?] Well, they've got their ideas about, you know me and things, and I know why, ..I feel very bad about it all, very bad, very bad.*

(8;19;27)

This compounded feelings of *"being alone in the world"* (8;33;31), of feeling isolated and led to anxiety and depression.

Many felt that the constant stress which they suffered as a result of worrying about their future financial circumstances, compounded existing health problems and felt that this worsened their health. Crucially, when worry over housing and financial circumstances was compounded by an acute episode of illness, such as a heart attack, a stroke, an asthma attack, or a fall, this had severe repercussions on their ability to cope. In many circumstances, it was not the severity of the illness which caused more long term problems, but the fact that participants *"gave up"* struggling to *"keep their head above water"*, and preferred to defer to professional opinion and eventually become more dependent on

health and social services. That is to say, their ability to adapt to problems caused by illness was impaired by a range of other factors which caused anxiety:

*Nobody's bothered, you know, nobody wants to know, nobody's bothered. There's so much to do, there's so much to get done, there's the garden, the house, the bills...it's getting me down...and now this .... I'll have to go in a home, that's what they told me.*

(6; 15;3)

This participant had suffered a minor Transient Ischaemic Attack (TIA) and was expected to make a good recovery, following a course of rehabilitation at the day hospital and also support from social services at home. However, she now felt herself to be very ill, and wanted to be in hospital, where she felt she had respite from the burden of responsibility and the need to make decisions which caused her so much anxiety.

*I need to be in here, in hospital. They don't think there's anything wrong with me, they don't, they think I'm putting it on, they think I'm saying I've got this when I'm all right, but you know. I know I'm ill, critically ill, but you get no help at all. But I know that because I'm so poorly, I can't be thinking about the house, the garden, I'm too ill*

(6; 33;16)

Perhaps unsurprisingly, this participant showed little interest in the concept of greater participation and having a role in decision-making. When asked how about what she thought would be happening in the next few weeks, she responded:

*I'm not sure I'll be here. It was very nasty, touch and go, I couldn't breathe, I was going like this [demonstrates laboured breathing] and gasping for breath. I don't think ahead, you'll have to talk to them [doctors]*

(6; 20;7)

For example, some participants were particularly anxious about having to supplement social services which they received by paying for additional services. They were concerned about how long their savings would last, and what would happen after this. Although, the fact that their children would not be able to

inherit, while this was very important to some participants in both their public and private accounts, some people in their private accounts suggested that this was more because they were uncertain about the future and what would happen to them after this money had been spent. This was obviously very difficult to adjust to and preoccupied many people's thoughts about the future. Consequently, in discussing outcomes, many people focused on financial aspects above health issues, as they felt that greater financial security brought with it better health and "peace of mind" (3; 12;9). Those with dwindling savings felt threatened and felt they faced a worrying and uncertain future. For those with greater financial resources, the prospect of deteriorating health, seemed less anxiety provoking than for those with few resources, but was still a significant source of anxiety.

Some participants mistrusted people who were paid to organise finances. This feeling made people all the more protective of their finances, sometimes at the expense of actually accepting help from independent external sources, such as bank managers or financial advisors, social services and charities, such as Age Concern. These participants became suspicious of people's motives for offering help, which may appear to outsiders as illogical, but given the experiences of the participants, it was possible to see how such adamant feelings of mistrust had arisen. This, however, meant that people denied themselves services and support which they might in other circumstances have found beneficial and helpful:

*[Do you have anyone coming in?] No, no-one. There was a woman that the social sent, you know, she came to clean Mondays and Thursdays, but I didn't like her, didn't like the way she looked around, you know, opening drawers and that. She was into everything. And you know, you don't know what they're saying, you don't know what they're saying. They could be telling any Tom, Dick and Harry about what you've got and where you live and what you've got and that - there's some real wrong-uns out there*

(31; 34;12)



The Disability Rights Movement have long argued the need for disabled people to have a greater income, rather than just for more services to be provided for them (Morris, 1993; Oliver, 1996). Similar calls have been made in the US for greater income for pensioners, although there have been fewer attempts to address this in the UK (Age Concern, 1992). More money was seen by participants to facilitate choice, and decision-making, in that people, in theory are able to consider what they need, and what is available, prioritise and ration accordingly to buy what they require, although in practice this may be more difficult. This in turn suggests that people are not as dependent on existing health and social services but have autonomy and control over more aspects of their lives, and tailor services to their very individual circumstances and needs.

### ***Having a useful purpose***

In addition to feeling socially integrated, participants alluded to the importance of having a purpose, or having a role in life which in turn made them feel valued and included. This was particularly significant for one particular participant - Mrs Mona. She had been a matriarchal figure, a foster mother to children over a twenty year period, as well as raising her own children:

*I took lads in who were up in the area on football sponsorships. They came from all over the country, to train at the club, and some of them were only fourteen or fifteen, some were older, but we had a big house and it was nice to have a house full*

*(7, 17, 3)*

She still lived in a large Georgian detached house in a suburb of the study town. The house clearly had many memories for her and was very much part of her identity:

*This house is full of memories for me, I still look at the stairs and can imagine them covered in mud and clutter, football boots, dirty shirts muddled up with the clean ones I used to put there for them to take up to their rooms, and the chatter, chatter, chatter - it was always **so noisy**,*

*always something happening, something to do, to sort out. Looking back it was twenty years of hassle!*

(7; 18;4) )

However, whilst she described a picture of chaos, it was clear that she enjoyed the experience and was immensely proud of what “her boys” had achieved, and in turn, of her contribution:

*I keep in touch with some of them, not all, but some of them, and I always look forward to hearing how they're getting on, at Christmas and that. They're all married now, with children of their own, even grandchildren, and very successful - one's got his own business and Jack works in a bank, so its very nice...I'm pleased if I could give them a start, you know, and help them in some way*

(7;20;13)

She had revelled in having a large house filled with young people, and had enjoyed the busy atmosphere, so it is perhaps not surprising that she felt lonely and unhappy now that she lived alone and the house was quiet and empty:

*“It's a love-hate relationship, I think now, ...well, in that I love this house - we bought it five year after we were married, and I've lived in it for forty odd year now and its been a very happy house, on the whole you know, I think. But it's a house that cries out to be lived in... this room especially is made to have a family full, do you not think?...Oh, but its so dreadfully quiet now, so dead, and I get so lonely. I'm ever so down. ....I clatter around and I'm so lonely, I don't see a soul day in day out, even though I live on the main road, see the house is set back and so I don't see anyone. And no-one calls. Not a soul. I sit in this chair all day, and I just cry and cry. I cry my eyes out,... I'm so miserable*

(7; 26; 9)

Her family, she said, had recognised that she was lonely, saying that “the house was too big” and they had suggested she considered giving up the house and going to live in a residential or nursing home, to “get company”. It had also been suggested by her GP and family members that she attended a local day centre for older people for the same purpose. However, while this may superficially appear to be a simple solution to this participant's problem of loneliness, as others perceived it, this solution would not necessarily achieve the a desired

outcome for this individual. For although she talked of the house as being empty, and herself as being lonely, during the discussion it emerged that she perceived she was lonely, not just because she had little company of her 'own age', but rather that she felt she had lost all meaning in her life; her role, her sense of purpose, and the empty house was symbolic of this, which is part of the reasons why she appeared to resent it so:

*I sometimes wish I could just get rid of it once and for all, sell up and move away completely. Completely away!*

(7; 29; 9)

Forced to abruptly retire from her previous role at 60 due to statutory requirements (she commented that she had both wanted and felt able to continue) she had found it particularly difficult to adjust to her loss and forge a new identity. The period following her enforced retirement had been followed by a series of episodes of ill-health, caused mainly by excessive drinking and resulting in her being labelled 'alcoholic'. Her moving to a residential or nursing home may contribute to her appearing to others to be less lonely, by providing regular contact with people, but she felt that this would actually compound the problem of her perceiving herself as 'old', and 'only fit to mix with old people', when it was youthful company that she enjoyed, and had been used to and encouraged practically all her adult life:

*It's no fun being old you know, you make the most of it while you're young, cos that's the only thing this worlds got time for*

(7; 16;31)

One must not ignore the often extremely powerful impact of larger societal forces on the relationship between age and achievement. In terms of mandatory retirement alone, we will never know how many potential achievements never saw the light of day because individuals at age 60 or 65 suddenly found themselves denied the resources to continue their work. In Mrs Mona's case,



when we discussed the health problems that she had been experiencing (and for which she was attending the day hospital) she did not mention her heavy drinking, saying only that she had had a series of small strokes and had problems with her liver. According to her medical notes, she was attending the day hospital to have physiotherapy to improve her walking - "unsteady gait" - which had deteriorated since her last stroke and for blood tests to monitor her liver condition. She perceived that she was going to get company at her daughters request. We discussed her treatment at the day hospital:

*I'm perhaps not as good on my feet as I was a few years back, no, but you expect that. I can get round the house all right, up the stairs if I take my time, ...and I never go out, so I manage okay*

(7; 14;22)

We discussed an improvement in her mobility as a result of attending the day hospital and what this would mean to her:

*Well to be honest, I don't think it would altogether make much difference to me, would it? I don't really know, but I think I manage okay now, I'm a bit slower, sure, but that doesn't really bother me*

(7; 15; 12)

Therefore, efforts at the hospital to improve her mobility and her perceived loneliness, while perceived by family members and health professionals to be important, were not perceived to be a major problem from her point of view. *From this persons perspective*, it would seem, the value to her of measuring change in her mobility was not great. Her mobility was not a priority issue to her, but there were clearly aspects of her life in which she would like to see change, given the opportunity. Whether these wishes, could be accommodated for given the present structure of provision of health and social services is an unanswered question.

### ***Somewhere to go, something interesting to do***

From the accounts it would seem that what was emerging was that it is problematic to make judgements about whether someone feels their life is restricted socially from knowledge of *what* activities they do. Do they visit family or friends? Do they go to church? Do they go to the pub? Do they go on day trips/ outings? Do they go to the cinema or theatre? Do family or friends visit them at home? It is the *value* that a person attaches to these activities that gives them meaning, as is the perceived *quality* of the interactions rather than simply the quantity of social activities.

The majority of the participants felt that their lives were restricted socially. However, what was interesting was that all participants did not identify any 'chronic illnesses' or their own health as being the single cause of this restriction. Of course, these illnesses definitely were felt to restrict their activities in some ways. For example, painful joints from arthritis restricted movement (Mrs Dawson), or an inability to walk long distances because of heart failure (Mrs Mona). In fact most participants seemed to accept the 'functional problems' associated with their chronic illnesses as an inevitable part of the ageing process. Some authors have stressed that social contacts and activities are to a certain extent dependent on reasonable health and functional status (Farquhar, 1994). Four participants specifically focused on day centres: grudgingly accepting that they would have to go to day centres as there were no alternatives, and it offered them only opportunity to leave the house.

### **Additional factors which influence quality of life**

The loss of a sense of self is a fundamental form of suffering for people who develop a chronic illness, since they frequently experience 'a crumbling away of their former self-images without simultaneous development of equally valued

new ones' (Charmaz, 1983). Charmaz (1983) attributes this loss of self to four major sources: living a restricted life because of the functional limitations imposed by the condition; the consequent social isolation; experiencing discrediting definitions of 'self' and the feeling of becoming a burden to others. The restrictions on their life that people with chronic illness experience may be externally or self-imposed. Charmaz (1983) suggests that people with a chronic condition often suffer disruption to their daily life which goes beyond the physical discomfort with which they contend and that while, they aim to protect their lives, they may do so at great cost to their self image.

Social isolation is a major consequence of a restricted life. Charmaz (1983) found that chronically-ill people often drifted into social isolation, because they did not have the time or energy to sustain social activities or relationships while contending with the functional limitations and treatment regimes which accompanied their condition; and the drift into isolation intensified as their condition worsened. Such definitions can be forced upon a person who is ill to avoid discrediting definitions of self.

### **Self esteem and self worth**

Measures of morale, depression and anxiety are widely used. However, characteristics such as self concept and self-esteem (Farquhar, 1994); outcome measures related to feelings are less common. Yet, feelings about one's life are intrinsic to subjective matters (Farquhar, 1994).

Coopersmith (1967) defined self esteem as self judgements of personal worth. Self esteem is defined by Robson (Robson, 1988) as a sense of contentment and self acceptance stemming from a person's own appraisal of their own worth, significance and ability to satisfy their aspirations. Fitts (1972) suggests that self esteem is predictive of a person's performance, since someone who has a clear,



positive and consistent self concept will operate in a confident, constructive and effective way. Some researchers (Rosenberg, 1991) argue that self esteem is a stable personality trait, unlikely to alter substantially unless a person experiences a life event serious enough to significantly alter his self perception. Others argue that self esteem fluctuates as a result of changes in a persons roles, expectations, performances and responses to others. Among retired people, studies have shown that men have higher self esteem than woman but age per se appears unrelated to it. Rosenberg (1965) reports that high self esteem is predictive of a number of psycho-social characteristics including reduced shyness, more assertiveness and higher levels of social activity. Conversely, low self esteem is recognised as a component of several psychiatric conditions including anxiety (Ingham *et al.* 1986) and depression. Self esteem, then, is a significant health issue, since it is related to other health problems such as anxiety (Rosenberg, 1991) and depression (Ingham *et al.* 1986). Self esteem, described by Rosenberg (1965) as self-acceptance or a basic feeling of self-worth, is often used both as an explanation for and consequence of psychological disorder (Robson, 1988). Few studies including older people measure self esteem, yet low self esteem is a common problem for older people and is linked to a range of 'health' problems.

The relationship between older people with chronic illness and self esteem has not been widely researched to date. A sense of control and sense of mastery in the context of chronic illness has been defined by Pearlin and Schooler (1978). These authors found possession of a sense of mastery was a key resource in managing stress associated with four life roles: marriage; parenting; managing household finances and occupation. They also found that a sense of mastery tended to be greater among woman than men, among younger than older people, among those with higher levels of education and among those with

higher incomes - concluding that it was closely related with achieved status.

Bearing in mind the threats that many older people have imposed on them, such as enforced retirement, plus life events such as bereavement it seems reasonable that a sense of mastery is sometimes reduced. Others take the view that mastery is among the personal resources on which people draw in the face of the threats posed by events and objects in their environment; that it influences their ability to manage challenges competently; and is conditioned by their past history of meeting such challenges (Turner and Noh, 1988). These authors found that among physically disabled people, the effects of mastery in countering the development of depression was clearly observable across all ages.

## **Management of identity**

Feelings of social isolation also linked to the theme of management of identity and this had implications for how participants perceived themselves. The concept of low body image is linked to low self esteem. Body image is the mental idea that a person has of his or her own body, and is an evaluation of one's size, weight or any other aspect of the body that determines physical appearance (Pruzinsky and Cash, 1990). Social impact studies have explored how older people are perceived by others and themselves. Society places much emphasis on physical appearance, and evidence from many studies suggest that people attribute stereotypical attributes based on appearance (Thompson, 1992).

In the early stages of illness, one participant recalled how she tried to keep up a physical and social appearance of being fitter or more able than she actually was:

*After my stroke I walked round the estate, and I wouldn't have my stick, I just walked round but I had to hang on to \*\*\*\*\* (husband)*

(12; 17;5)

The cultural norms and fashion dictums which are forced on most of us are widespread. The social norms which dictate what we wear, how we look, how we act if we are to be 'accepted' by the wider society are numerous. And stereotypes are formed which further perpetuate the enforced values on others. Thus, a stooped walk is no longer considered culturally acceptable as it is supposedly the norm to walk upright:

When we are old, and we require help to sustain this culturally-imposed technique, we are fobbed off with a dreary yard or two of battle-ship grey clinical steel on which to hang

(Midwinter, 1993, p42)

Also, expressions such as 'mutton dressed as lamb' are commonly used to describe an older person wearing clothes which stereotypes suggest are not suitable for a person of that age, or conversely, are only considered suitable for someone who is younger. Older people are, of course, part of this wider society and in many ways conform to the stereotypes, although this may be at odds with how they are actually feeling or what they felt was practical to do.

*I like being tidy, I like been neat and tidy. But I can't eat certain foods now, my hand shakes and I spill it down my front, and ..it is embarrassing for me.*

(12; 7; 9)

One participant had been an active member of her local church for over forty years, and, with her husband, had been a member of the Parochial Church Council (PCC). Indeed, she had been active in a variety of prominent community roles, including Chair of the Woman's Guild and Chair-woman of the Inner Wheel (a branch of the Rotary organisation). This she felt had given her :

*... a certain standing - we're (her husband and her) well-known round this area. We know a lot of people*

(12; 33;5)



She was clearly proud of her community role, and valued the range of contacts she had established over many years. Much of the first interview was spent discussing her various experiences and the pleasures and challenges she had derived over the years from both organising and participating in a variety of events, and from them. However, during the second interview, indeed, towards to later stages of this interview, we began to discuss how she felt now these roles and contacts had ended and why they had ended. Initially, when discussing her now infrequent attendance at Inner Wheel, for example, she insisted that she felt it was important for younger people to have an active part in the organisation:

*I believe in knowing when it's time to move over, and let others have the experience, because that's the only way they are going to learn, if people like us, move to one side and give them the opportunity*

(12; 36;21)

However, she later said that many of her friends and acquaintances still attended the group on a weekly basis for lunch, even though they were no longer part of the committee. The discussion moved on to why she did not attend in the capacity of an 'ordinary' member:

*Well, it's difficult to get there, I've got no transport now I've had to sell the car: (pause). It's difficult to get there. (pause) someone did offer to pick me up and drop me off again, but I'm not used to that and I prefer to be independent. I always have been*

(12; 37; 4)

Other modes of transport were suggested, such as taking a taxi to get there and back, but the participant then went on to describe how other factors mitigated against her going to the various social activities, which she previously had thrived upon. She described how, since her first stroke three years ago, she had experienced some difficulties with her walking, in that she felt a little unsteady when she first got up out of a chair and felt nervous about walking 'long distances':

*...I'm very shaky sometimes for the first couple of steps, usually, just before I can get into my swing....I'm concerned about falling, yes, (pause) I think I'm more bothered about onlookers if I was honest...everyone staring, all rushing over to help, I can just imagine it and I'd hate that, I'd loathe it, all that attention. It doesn't bear thinking about, showing everything*

(12; 27;6)

She felt conscious that her speech was sometimes a little slurred, especially if she felt tired or nervous, and she perceived that people had changed in their reactions to her. She felt that her shaky physical appearance, and her speech difficulties meant that people treated her with less respect, and treated her "as if I'm just another old dear". This was clearly a very private and emotional topic - one which she had never articulated before - and which unearthed feelings of loss; loss of sense of self; of self-worth and loss of 'social position'. In order to salvage, as she saw it, what was left of her self respect, she preferred, indeed, chose, not to attend such functions:

*... so, I don't go and then it can't, well won't happen, can it?*

(12;37;11)

She felt strongly about her personal appearance. She had (for forty-five years) had her hair 'washed and set' once a week at a local salon, and had enjoyed shopping for and buying and wearing new clothes. She had prided herself on being 'up to date' with the latest fashion styles and colours, and had had a keen interest in buying fashion magazines to note any changes. Now, because she was unable to drive and was subsequently limited in her mode of transport, and in her confidence about shopping alone, she could not do this. Someone now came to the house to do her hair, which she said she enjoyed and was pleased with, but was frustrated by her lack of opportunity to go out shopping. Her daughter had brought some mail-order catalogues for her to browse which she felt was a compromise:

*I've bought a fair bit from that one (points) - and it's good quality clothing, on the whole, but it's not the same as going to the shops - do you buy from catalogues like this? Well, then you'll know what I mean, but it's not, is it? They never fit, you can't get a good idea of the fabric, or the colour from the pictures. and there's no choice...and it's the bustle that I enjoy. The people. I even don't mind the queuing up at the till*

(12; 40;29)

Her whole life had altered and she found it difficult to adjust. However, the consequences of her stroke did not cause all the 'problems': rather these were compounded by the barriers in the environment and the perceived reactions of family and friends.

*Home environment: service needs and standards of care*

Participant's social environment was important and for the participants who lived in their own homes, this was a particularly important part of their identity. Their home was a private, personal place in which people felt they could 'be themselves', and talked of the home giving a sense of 'protection'. For people who were ill and received support, this function was altered as a consequence of requiring increased levels of support for their illness management. For some, it became a stressful experience to have relative strangers, nurses, occupational and physiotherapists in their home, and moving between the lounge (or sitting room), bedrooms and kitchen. This threatened their sense of identity and independence. Items of equipment such as walking frames, hospital beds and hygiene supplies took up space and gave homes a cluttered unfamiliar look and feel:

*You see those boxes over there? I've already used half of them, they were piled high before. I'm not complaining, but it's as if your home has been taken away from you. It's a mess really. It used to be lovely, just as I wanted it, but it's like a store cupboard now.*

(9; 5; 7)

*Of course when it's your own house, you can swap things round when it makes it easier for everyone. It doesn't look like a home but it's what's easiest that matters. Anyway, no-one comes to see it, only family and they know the situation*

(18;1;6)



*Come and have a look - it's like a hospital in there*

(12;6;11)

The experience of illness created disorder, and the familiar fabric of domesticity had been transformed into something unfamiliar and chaotic.

Being personally clean and comfortable, a clean and tidy personal appearance were cited as being important 'quality of life' outcomes for individuals. Similarly maintaining a good diet, having help with cooking or shopping were also identified as important aspects for services interventions to assist them to live independently. Help with the housework to maintain a clean and comfortable environment was also identified as being important. Help from any source was valued by most participants, providing that it was on their terms. This usually limited the contribution that could be made from health and social services. These are domains which are adequately covered in many existing outcome measures (Barer and Nouri, 1989; Mahoney and Barthel, 1965). The experience of illness was not simply couched in terms of the language of personal problems with disability, for example, an inability to walk, to wash, to go to the toilet, as many of the existing measures of outcome for older people tend to focus on (Barer and Nouri, 1989; Mahoney and Barthel, 1965). It is important not to underestimate the importance of these desired and expressed domains as outcomes to participants. However, at the same time it is crucial to ensure they are placed in context if we are to appreciate their true meaning.

All participants found it difficult to discuss service needs, impacts and outcomes in abstract terms. Initially then, discussions focussed on existing experiences and existing input and the impact this had on their lives. Discussion of these concepts raised issues both about standards of care, and older peoples expectations of services. Participants found it difficult to conceptualise

hypothetical interventions. Services such as 'meals-on-wheels' and home-helps were familiar concepts. They found it difficult to think imaginatively about alternative services which might meet their specific needs. Some felt their choice was severely restricted and few people seemed to discuss 'needs-related' services. Participants appeared to expect no more. The public account is gratitude for any services for older people. However, the private account revealed a certain exasperation about the services offered to help them live independently. Making judgements were difficult, though, as their expectations were so dulled. They found it particularly hard to think in abstract terms and felt burdened by the immediacy of the situation.

### **Negative experience of older age**

The terms used to describe experiences of ageing in the public accounts were largely negative. Participants talked of the 'problems' of old age, i.e. the problems that they perceived older people posed, both as individuals and collectively on society, and of the burden of the older population. Older people in these accounts were stereotyped and assumed a common identity. Old age was presented as synonymous with ill health and decline, even if this had not been their own personal experience. The private accounts in contrast illustrated greater diversity in both beliefs and experience. Where participant's public and private accounts merged, it was clear that for these people, illness along with feelings of burden, a lack of self-value and a sense of gratitude and indebtedness dominated their conceptions of 'a normal life'. For these individuals, ageism had become a reality, and they appeared to increasingly accept this as the *status quo*. Their perceptions of 'a normal life' were characterised by expectations of limited social opportunities and of ill health which would further restrict their activities.

In this way, they conformed to the medical model of disability, and focused on themselves as individuals, on their own perceived 'failings'. These individuals were also more likely to express a feeling of low self-worth:

*My legs have gone, just useless. I can't walk properly. I'm just a nuisance to myself and everybody round me. We're all just a bloody bind*  
(17; 4;5)

This apparent acceptance of the devalued position of older people in society mitigated against them making conscious decisions about need and outcome. The lack of value and lack of belief in their own abilities and a sense of fatalism about events meant that these people also seemed more likely to have very low expectations and express negative thoughts about any suggested possibilities for improvements:

*Why no, it's never going to get no different is it, now. There's nowt to be done about it. I was hoping to make my nieces wedding June next, but I'll never get. I won't be here then*  
(18, 26,9)

The major difference between participants in their experience of illness, arose from their different attitudes towards, and expectations of, retirement, and from the strategies they employed for coping with their situation. For some, it was the severing of the connection of relationship as they had known it, and wanted it to be, that had the most negative effect on their experiences of coping with illness. Participants who based their identity in retirement on the idea of attachment, of being part of a couple, experienced the erosion of their identity through physical incapacity as an erosion of their own identity. At the same time, wives found it difficult to assume another identity. Although the relationship as it was had ended, the status of 'wife' persisted. Wives carried on providing the care that they had instinctively begun when their husband became ill, but had, however, to reconcile themselves to a change in their own identity and status. There are few



formal and societal mechanisms by which wives in this position can grieve for the loss of their husbands (Lezak, 1978; Crossman *et al.* 1981). For in reality it was not a loss of physical being, but a loss of the former identity, with which the wives were faced. A part of the problem of identity, often lay with the way they saw their own world as having shrunk and the way, crucially, that this was reinforced by other people:

*I seem to have lost myself in all this illness and helping*

(2; 9;9)

*But it's just that you can't do what you want to do, neither of us can. I suppose it's because you don't expect it, you don't plan for it and so it's just a shock*

(31; 16;10)

This latter quote questions existing theories that stress that older people plan for such events and so are better placed to adapt to them reflecting societies ageist attitudes to older people:

*You miss the freedom, you can no longer do what you want, you don't matter anymore, it's all with regard to him. I've got that way, I don't know what I would do for me now, I don't seem to count, you know what I mean, it's like my only purpose, to do for him*

(2; 14;12)

This concept of freedom was linked to themes of independence:

*Enjoyment out of life! (she laughs) you must be joking. The only thing I get is on a Saturday when I go into town, sometimes I think I'll go and treat myself. I never come back with anything, because I've no time to look. I'm all wound up. You can't look...*

(31; 30;27)

Perhaps one of the biggest contradictions for these people, was endeavouring to care for a person whose past character and qualities had to be reconstructed everyday and caring took on a temporal quality. One participant was caring for a husband who had a stroke. She herself was attending the day hospital for re-

balancing medication for heart problems, and also for treatment for depression.

She reported changes in his personality and emotional liability:

*Now the district nurse comes in the other day and he holds out his hand to her. He doesn't to me. I get pushed away. He does, he pushes me away. When he first had this stroke he used to grab my hand like that and squeeze me. He doesn't do that now. I think they blame you for it myself, well you feel guilty, maybe its me and not him. Anyone else that come they get a lovely smile.*

(17; 15;12)

In terms of thinking about what outcomes they would like for themselves, this person focused on the relationship with her husband, which was of paramount importance. Her own health problems took on less significance, she felt, in comparison. However, because of a lack of emotional support in her home environment, she increasingly seemed to look to the health professionals involved for support by focusing on her own health problems as a method of mobilising it.

### **Confidence**

The theme of lack of confidence was one that appeared in each interview. This could be in terms of confidence about activities, such as going out alone, or in terms of ability to do certain tasks. However, it was also discussed in more abstract terms, for example, in terms of confidence in ones beliefs or confidence in how individuals felt they were perceived by others. This section examines the value of confidence to participants in facilitating coping with everyday life, the significance to them of a loss of confidence, and the sources of confidence.

Several of the participants who were attending the day hospital identified problems with general mobility - problems with walking long distances and a fear of falling. These participants were seeing the physiotherapist either once or twice a week for rehabilitation. Their perceived benefits of this were discussed, and some participants were clearly able to focus unprompted, on areas where

they perceived that they had been change and, significantly, what they attributed the change to:

*It (the physiotherapy) does me some good. I feel more confident.  
Stronger*

(1; 3; 15)

*Well, I used to be scared of falling, like, when I was out and that, cos when you're inside there's always something to grab on to (demonstrates), so I think she's helped with that*

(28; 6;16)

They also made the link between short term and long term effects, once the intervention was withdrawn, voicing their concerns as to whether any change would last or if it would be a short term benefit:

*I feel more confident, but then, I've only been going for a couple of weeks, so, I don't know if it'll last*

(19; 7; 4)

Participants felt that the physiotherapy treatment that they received helped them to feel more confident about walking, and reduced their fear of falling, which they identified as the main barrier to them going out alone. However, as this last participant identified, the *length* of benefit was variable, as he went on to illustrate:

*I feel better in myself when I'm going up to the hospital and seeing \*\*\* (physiotherapist). They're all canny, the lasses on, they look after us and we have a bit crack.....aye, I think I feel a bit brighter about me walking, me legs feel like they've got a bit of iron in them, like, and I think it's just from having to use them, you know. There's a lot of walking, more than I do, the lads come in the ambulance, and then you've to walk from the ambulance to the room where we all sit.....but I dunno, it's alright there see, cos there's always plenty of people with you, and it makes you feel as if you can do it, as soon as I stop there, there's no-one to take me out so, no, I don't know if it'll last*

(29;12; 9)

Another participant echoed these sentiments:



*I feel a bit more confident that I can get from A to B, without not making it, but I don't go anywhere, and so my legs are very weak*

(19; 7;9)

They felt that support to improve their walking was welcomed, but that the benefits were short-lived, as with no-one to go out with they were in a vicious circle, and would not feel confident long term:

*It's a terrible thing. When you've had a knock back, like I had*

(26; 6;21)

Another theme which emerged, then, from the interviews was the importance of rebuilding confidence after an event such as a fall had occurred.

One participant who lived alone, described how she had gone out of her front door, and down a step to stand in the front street:

*I fancied a breath of fresh air - well, as fresh as you can get living here. The front room gets the sun all morning, and then I get it in the back all afternoon, so I'm lucky really.....so, I got down the step, and you have to lift your leg over, 'cos there's a bit raised up, and I stood and I used the door, well the door frame, as something to hold on to keep me steady, but my hip ceased up, I couldn't move and I was stood there like a right lemon for, oh, hours, and I started to shake with the pain, from my hip, it's this one, ....and no-one passed, 'cos the kiddies were at school, and there's only the three houses you see, we're very sheltered. But oh I was frightened, I can't tell you, and I thought well, what if that happened and I fell and broke my hip and couldn't move. Who would know? How would I get help. Oh it did knock me, and I won't go out now.*

(44; 5;14)

In terms of expectations of retirement there appeared to be gender differences, in that men interviewed appeared to have approached retirement with few, if any, firm expectations of what life was going to be like, and so seemed less disappointed about the outcome than the woman interviewed. Men found it difficult to talk about care other than in a fairly structured and distanced way. They used the structure and language of work more extensively than woman to describe their care, and rarely touched upon their emotional responses to relationships that had developed. There was a feeling that men in general were

more unaccustomed to discussing their feelings, arising perhaps from their participation in work and lack of experience in articulating such emotions. Men seemed muted by their lack of vocabulary with which to describe their emotions, simply because the language of care did not form part of the dominant communicative system of their world (Ardener, 1989).

## **Dominated individuals**

A small group of participants were termed 'dominated individuals'. These were participants who seemed to *genuinely* prefer to defer to others opinions and preferred decisions to be made for them. In these cases, it was difficult to separate the public account from the private account. They appeared to want no part in decision making, or participation and very much seemed to prefer decisions to be made for them. These were particularly difficult interviews, in that participants in this group felt they had little to say, and were uncertain about what was happening, and what might happen in the future. There were several possible reasons for this type of behaviour, which are discussed below. There seemed to be no specific gender differences within this group, although all participants in this group were in a lower socio-economic group. Some of the participants lived alone, some with relatives or spouses. The power relationships that developed, therefore, could be with formal carers, or informal carers, with health professionals or with family members.

### ***Relationships with others***

These participants seemed to be very much managed and controlled by the people who cared for them. There was also a distinction made between those participants where they reported little attempt was made to hide the degree of control carers exerted over care, and those who were managed behind a facade



of choice and shared decision-making. This distinction is *overt control* and *covert control* because of the qualitative differences between the accounts.

### ***Overt control***

For these participants, they were in a position where they were overtly controlled and the management of their care was defined by others. They appeared to be treated as exclusively dependent and appeared to be given little part to play in making decisions about their care, either personal, health or social. In some cases this appeared to be due to the person's who cared for them desire to care, rather than stemming from the participants actual need or desire to be cared for. In all but one of these relationships, participants appeared to accept the restrictions placed upon them and the accompanying loss of control.

These participants said they had suffered a decline in their abilities. Mrs Carter had become suddenly ill following a stroke, and had still not recovered the use of her left arm. Mrs Grainger had a chronic respiratory problem and severe arthritis in her hands and knees. Mrs Shannon had phlebitis in her legs and experienced short periods of confusion, which seemed to lift with as little warning as they arrived. Mr Geraint had suffered a series of heart attacks and was very short of breath on any exertion. Mrs Alford was slightly deaf, but appeared otherwise physically fit. She said she was forgetful, but during the course of the interviews, as her daughter came in and out of the room, it became evident that Mrs Alford strongly contested her daughter's views and definition of her health and need for care, and the suggestion that she was 'loosing her memory and unsteady on her feet and going downhill'. This was not immediately apparent, Mrs Alford said very little when her daughter was present and appeared passive and uninterested. Her views, both private and public, only emerged after several interviews, and with the building of trust and relationship between interviewee and interviewer. But, even then, it was difficult to gauge exactly how much



progress had been made, and the interviews were short because these participants grew tired easily and it was difficult to maintain momentum.

***Dominated individuals: decisions about care***

All the participants who were overtly controlled experienced 'prescriptive care'; the people who provided care for them had adopted a prescriptive approach to care. They had a rigorous schedule of activities imposed on them, aimed at promoting their health and fitness, or carers seemed to protect participants by anticipating and meeting their needs for them. This involved the management of the household as well as providing personal care. This was clearly felt to be provided with positive intentions: participants said they felt this was directed at keeping them active and well. Mrs Carter's husband had taken over the management of her care following discharge from hospital after her stroke. Before discharge, the physiotherapist had given Mrs Carter a demonstration of the exercises necessary to maximise limb movement. These exercise became a rigid and rigorous aspect of her daily care. Initially, Mr Carter explained:

*It's quicker if I help Maeve get dressed and to get washed but in fact I make her struggle for her own sake - I don't do it all for her because I know it is good for her to try and do it herself. I steel my heart and make her walk although it's very, very hard for her. She's got to do her foot and arm exercises, I'm always at her 'Are you doing this? Are you doing that?'.*

(26;33;9)

Mrs Langton and Mrs Alford were similarly largely controlled in that instead of being encouraged to keep active, they were 'protected from harm':

*He just tries to make life as easy for me as he can. He knows what's best. When I have attacks [angina] he makes me stay in bed, I don't have to, but he says 'stay in bed and have a rest' and then he lets me have a bit potter around.....If I didn't do that I would struggle to do things and so he's bossy for my own good to make sure I don't.*

(23;6;17)

Mrs Alford was protected from the perceived risks of independence by a husband, as well as providing the carer with an important sense of being needed. This relationship had clearly been similar in the earlier days of marriage, with the participant being the more passive partner. From their accounts, she appeared to have accepted what her husband suggested, or decided, to accept the situation largely without question. It is therefore, perhaps, unlikely that this participant would be keen to make decisions about her health care and might have firm ideas about what she would or would not expect. She had been socialised into a position where others made any big decisions about her life and lifestyle for her and she appeared to be content to trust their judgement and their motives for doing so. With regards to her recovery, she said she did not know what to expect, or what was happening. She was attending the day hospital, but was uncertain as to what she was going for, or what the intended outcome was. She seemed indifferent as to future possibilities, preferring to leave responsibility to her husband and health professionals:

*I don't know. I don't think so, but I don't know really. Whatever really.  
You'd need to see Alf, or Doctor*

(27;6;16)

Another participant, Mrs Mortimer, appeared very tired and weak - she had been out of hospital for only three weeks when interviewed following treatment for heart failure. Several major decisions regarding her care and had since been made, but she recognised that on occasions she was too tired to fight and would agree to anything:

*I can't concentrate on anything. I've been so poorly. I feel terrible. I've got no fight time, so I just say : do what you think best*

(35;26;1)



These feelings were not unusual amongst such participants. The times when she felt too physically ill and tired to make major decisions and therefore put greater trust in others around her, was the time when the most significant decisions regarding her future circumstances were made by others. Too many changes were made too quickly for the person to adapt to, which added to their feelings of disillusionment and disempowerment, to a point where she felt *'you just give up and think, this is it, this is the end'* (35;4;19). Following this, it was particularly difficult for this person who felt she was very ill to find motivation and to begin to think positively about the future, about positive outcomes. The only outcomes she anticipated and expected, were deterioration, loneliness and death.

Many participants seemed to find the timing of any change difficult to grasp. One participant had been in hospital for 6 weeks and had only been discharged home for five days when she was interviewed. She had been told the previous day at the day hospital, that she could not expect to see any sudden improvement and that it would be another six weeks or more before any change might be visible. This distressed her immensely and she was tearful throughout the interview. She had interpreted this information in her own way, and had concluded that there was little, or no, chance of her ever improving. Health professionals had advised her that her condition would not improve, and this had an unintended but definite negative effect on how this person conceptualised outcome:

*they don't say it in such terms as you would know but I could tell from her look that this is, there is nothing, well that it is this*  
(25;22;8)

For some people, the effects of their illness seriously compromised their ability to live independently, as they defined it. In these cases, it was particularly difficult to engage participants in a discussion of choice and participation, and to identify



desired outcomes. Three participants had suffered a stroke in the last two years, four participants suffered from heart-related problems, and all had other chronic illness in addition to the main reasons that they were attending the day hospital. These participants illustrated that the existence of chronic illness, could take away some of the choice that may be available to other people. These participants said they had little or no idea about what they expected from the future and were also more likely to be negative about the future, when they did express an opinion. They expressed feelings of disempowerment and helplessness. For this group, talking about choice seemed to them artificial as they did not perceived that there were options open to them. It was this group that engaging in discussion about treatment decisions and service options seemed especially difficult. It was unclear if the discussions ever progressed beyond the public account, to reveal more private accounts. This was not necessarily due to lack of skill on the part of the interviewer. Other possible explanations included that this group were resigned to a life which was severely restricted by illness, and had been used to this for long periods of time which may influence their ability to consider future outcomes.

Participants tended to be compliant and found the their recent hospital experience depressing and stressful. This emphasises the way in which care can actually be alienating. Ross and Mirowsky (1992) suggest that alienation may arise from a sense of powerlessness, attributable to the fact that 'one's efforts cannot improve one's outcomes'. Those participants who contested other's attempts to control them, found the experience stressful and frustrating, but had not become depressed by it. They appeared to feel more powerful, than other participants and probably, according to Ross and Mirowsky, also felt less alienated by the experience.

This feeling that '*one's efforts can not improve one's outcomes*' is significant here. Implicit in this is the feeling that no improvement is possible, and that therefore any outcome will be negative. Also, another implicit assumption in this is that any deterioration or improvement is due to factors beyond one's control. The theoretical model which has been most widely utilised to explain institutionalised older people's passive, dependent behaviours and subsequent depression is the learned helplessness theory (Seligman, 1975). This theory postulates that a condition of helplessness develops when individuals experience uncontrollable life events, believe they can do nothing to change the outcome of these events and develop the inappropriate expectations that outcomes of future events will also be beyond their control (Seligman, 1975).

Convinced that there is no use in responding, these individuals demonstrate motivational deficits such as apathy, listlessness, a decreased incentive to initiate action and 'giving-up' syndrome  
(Seligman, 1975)

Also, these participants seemed less likely to perceive success when it does occur, less likely to see positive outcomes. Finally, according to learned helplessness theory, individuals experience emotional deficits, including feelings of hopelessness, loneliness, social withdrawal, irritability and insomnia. For these participants, any discussion of outcomes focused on very negative expectations, usually including death. Most of these participants said they felt depressed and anxious, and some said that death was their desired outcome as they no longer wished to live:

*I'm dying. I'm so ill, I'm so very ill. I want to die. I don't want to be on this earth any more. I want to die*  
(25;31;7)

This posed a particularly difficult dilemma for health professionals and for carers and relatives. This participant had heart failure, which resulted in her legs and

ankles being very swollen and slight breathlessness on exertion. However, she had until some weeks back lived alone without support in her own home. She presented a 'problem' to health professionals who had identified her problems as psychiatric, but, according to this participant, they appeared to have little idea of how to tackle this persons problems, tending to prefer to believe that she was malingering and exaggerating her symptoms.

## Summary

Physical illness alone, then, is clearly not enough to explain how people themselves felt about outcome. In order to understand why older people can appear apathetic to attempts to involve them in discussions about outcome, it is necessary to examine control strategies which they adopt to help themselves cope with the difficult situation they find themselves in. Crucial to further understanding is the concept of control, and the persons perceived ability to control events.

Participants described a lack of positive messages about their situation. Positive adjustment to illness has been associated with taking responsibility for the illness (Seligman, 1975). If participant's appeared to have accepted responsibility for their illness, but desired to also take responsibility for control of their subsequent health care, they also appeared to expect better outcomes. One of the key questions, then, became, not just 'what outcomes do older people want?' or 'how do older people think about outcome?', but what people *influences* outcome, and crucially, which outcomes do older people perceive are controllable, and why?



## Chapter 15

### Experience of health care structures

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The effects of living with a chronic illness or a combination of chronic illnesses has been documented in chapter 4, along with the experience of growing older, and growing older with chronic illness (chapter 2). An appreciation of the effects of these issues, provides a framework within which the perspective and experiences of older people can be understood.

We have seen in previous chapters *what* older people said in the interviews that they valued, and why. We know how important it is for them to feel in control of a situation and what they would value as important broad domain outcomes.

However, from participants' accounts, it is clear that the onset or development of chronic illness challenges their sense of control, their sense of mastery (chapter 2). Their relationships with health professionals also influences how they cope with chronic illness and how they perceive the future. Many felt the consequences of chronic illness are compounded by the attitudes of health professionals towards them, not simply because they are ill, but because they are *old*. This next section describes older peoples accounts of coping with chronic illness, their relationships with health professionals and the role of information in helping them to understand their circumstances and how they interpreted change. It is illustrated how the concepts of 'self-help', 'empowerment' and 'uncertainty' are debated as part of the process of coping with chronic illness.

For example, through the provision of appropriate information, it is argued, patients are empowered to manage their conditions effectively.

Many of the themes which emerged from the focus group discussion were echoed in the focus-interviews. The main issues which emerged from the focus group discussions were themes regarding the *process* of care, focusing especially on themes such as the relationships with health professionals; issues around information and knowledge; and also attitudes to participation in health care decision-making. Within these broad categories are sub-themes which are central to them, such as language and vocabulary, concepts of power and control, choice and dignity. These issues were further explored and reflected on in the focus interviews. There was an imbalance in the quantity of data generated on these topics. This may reflect that such process issues were important to participants and therefore stresses the importance of understanding them. However, it could reflect the fact that people were uncomfortable and unfamiliar with discussing 'outcome' directly.

Certainly, in this section, the analysis turned to discussing what people *expect* from health and social care, and what relationship these expectations had on how they conceptualised outcome. What factors are important in identifying outcomes from the perspective of an older person?

## **Obtaining and interpreting information**

### **Coping mechanisms**

All the participants in the study were coping with chronic illness to varying degrees. Coping is defined as the cognitive process which enables an individual to tolerate the effects of illness (Bury, 1991) and is an important buffer, maintaining coherence and personal worth in the face of disruption. The

psychological literature on coping with chronic illness is grounded in the concept of reducing anxiety in vulnerable adults who are potentially exposed to a stress stimuli. Lazarus and Folkman (1984) propose that evaluation of illness as a stress consists of a primary appraisal of the relevance and seriousness of the event and a secondary appraisal of coping resources (Lazarus and Folkman, 1984). They claim that the *meaning* of illness to the individual is more important than its nature. The evidence suggests that patients' illness cognitions influence how they make sense of their condition (Leventhal *et al.* 1980; Johnston and Marteau, 1990; Marteau, 1989)) and aid understanding at the different phases of their illness trajectory (Corbin and Strauss, 1991). Thus, illness cognition's are a prerequisite to coping strategies.

Paradoxically, there is a widely held belief amongst doctors that their delivery of information to the chronically ill creates a 'fully informed' and 'compliant' individual (Ong *et al.* 1995). Patients displaying a poor understanding of their condition (Street, 1991) or not conforming to prescribed treatments are labelled as deviant or non-compliant (Ley, 1989). Unfortunately, very little qualitative evidence exists within the medical literature, on older people's views about the information they receive, and its impact on coping. Consequently, it is difficult to discern what older people might need in terms of the standard of information, or the mode of delivery. A lack of understanding of how the person interprets the information to make sense of it in their specific context is also important to know.

Carver *et al* (1984) and Folkman (1986) suggest that the distinction between problem-focused and emotion-focused coping is too simplistic as is the theory that people adopt intrinsically adaptive or maladaptive responses. Recent evidence suggests that the response to chronic illness is dependent on a number of factors, including situational characteristics and resources available to the



individual (Lazarus and Folkman, 1984; Folkman *et al.* 1986). There is now increasing conceptual convergence among researchers towards this approach.

As well as illness cognitions, adjustment to illness is a significant element of the coping process. Two components of this concept are the extent to which patients retain their normal roles in society and the way in which they incorporate the disease into their way of life (Radley, 1996). Leventhal *et al.* (Leventhal *et al.* 1980) proposal of the 'self-regulatory model of illness behaviour' maintains that people cope with illness in the same way as with other problems. Satisfactory information provision is perceived to be a contributory factor in their empowerment (Sharp *et al.* 1992) whilst frustration and increased stress result from unsatisfactory information provision.

## **Managing symptoms and uncertainty**

All participants described how they had sought to 'make sense' of their symptoms, often for many months prior to presenting to health professionals. They described experiencing symptoms which they were concerned about, and being uncertain as to what the problem was. Whether people sought medical advice for symptoms when they first appeared seemed to depend upon their severity, and how they perceived them. Many initially 'worried alone' while attempting to 'normalise' their early concerns. When the symptoms were relatively mild, they attributed them to something relatively ordinary in their lives:

*... I've had a lot of infections in my water for along time, I'm always at the doctors for it, and at first I thought it was going to be, to do with that ...but it was a lot worse than before, than it had ever been, and so I was very worried at the time*

(7; 44;6)

*I remember having a runny nose ...and thinking perhaps I'm getting a cold*

(18;15;8)

*a couple of days before I'd been cleaning the kitchen windows, and knocked my leg when I was getting down off the stool, I just clipped the edge....and so when she told me about it [swelling on leg] I just thought it was that*

(6;17;8)

These symptoms were dismissed as symptoms that they had previously experienced and it was this experience which informed their health beliefs as to what the problem was. Others, drew on knowledge of others condition to make sense of their situation and to give it meaning, sometimes situating it in their family context or as part of what they perceived was part of the natural ageing process:

*my mother was troubled with her breathing, and so were my brothers ... I never really noticed a difference really, I just put it down to getting old*  
(6; 18;5)

Accounts from participants were characterised by the need for formal confirmation that their concerns about their specific problems were justified, and wanting *explanations and support* from professionals. This legitimised their concerns. When their own explanations for the symptoms no longer seemed plausible, often urged by carers or family and friends, they decided to seek medical support. They talked of *'knowing deep down that something was wrong'*, but lack of support and their own *'failure'* to adequately define or articulate their early concerns, meant that some made several approaches to professionals before being taken seriously. However, people in the empowered participants group were very persistent in their efforts to mobilise professional support:

*I could hardly lift my head up, and I'd had the doctor, oh, three or four times, that week, and he just fobbed me off.... He thought I was putting it on you see*  
(11, 10, 7)

Mrs Royale described how she called her General Practitioner's (GP) surgery regularly in an attempt to mobilise formal support, but this strategy of persistence was quite rare. Most participant's experience was that if they failed to engage formal medical intervention, they also received diminishing informal support as

friends and relatives lost interest in their concerns after reassurance from professionals had been given. In the face of scepticism from more than one source, some reduced their efforts to get their concerns taken seriously until a worsening of symptoms, and subsequent crisis, prompted further action:

*... then about, it was months later, the doctor came on a night ... I was grey ... and they took me to the hospital ... where they told me I'd had a stroke"*

(11,10,19)

Positive behaviour changes, increased knowledge and reduced anxiety are reported by some authors (Cook and Noteloviz, 1991; Vignos *et al.* 1976) in patients who received written and verbal information. However, far more significant increases in knowledge are received for those patients who received verbal reinforcement of written information (Masur, 1981). Acknowledging uncertainty's complex, cognitive stressor effect, Cohen *et al* (1993) emphasise the importance of information, assistance and support from health care professionals to minimise stress and uncertainty (Cohen, 1993; Mast, 1995):

*It's the not knowing that kills you, I think you always tend to think the worse, .... but until you know you don't know"*

(1;4; 7)

Alongside the uncertainty about specific symptoms and clarification about exactly what the illness was, participants also emphasised being concerned about how these might affect them and their families:

*I worry about how Jimmy (husband) is going to cope ... if I get worse and can't help*

(32; 17;26)

*... there's so much to think about, you don't realise how much you do until all of a sudden you're not there to do it ...*

(12; 4;19)



They were also fearful about the long-terms consequences and the implications again for both themselves and also other family members. This was a great source of anxiety, and threatened their sense of control:

*My greatest fear, is that I'll have to go into a home. My mother was in one at the end, and that's what I hope most, that they won't have to see me in one of them, like I did*

(20;14;9)

Accounts from participants in the *reluctant collaborator* group were characterised by a negative view of the consequences of the future. These views were formed on the basis of their own past experiences and beliefs formed over the life course. In line with their public accounts, these participants had a negative view of ageing in general. The outcomes that such people anticipated, not just their own *health* outcomes, but also service outcomes, tended to be formed around narrow, stereotypical ideas of what they perceived would happen to them. The concept of uncertainty, then, was important to older people in terms of thinking about outcome, but this was not simply in terms of uncertainty about the chronic illness trajectory. There was a certain air of acceptance about the decline which all participants associated with ageing, and the chronic illnesses which they perceived almost inevitably accompanied it. The *wider social and economic consequences* any change in their condition may bring seemed to be of more importance:

*these legs won't go down, they won't go down now and I won't be able to manage, I know I won't, I know that, I don't need anybody telling me, I know that on my own. I'll have to sell up, won't I, I'll have to give it all up*

(8;16;8)

*nobody wants to know, see, nobody wants to know, nobody. Not when there's illness, see, not when you're bad, not when you're old and knackered. No one comes. It'll just me staring at the four walls*

(9;15;8)

Individuals in the *dominated participants* group, felt that the problems that they were experiencing, while they acknowledged that they were medically treated, were actually 'old age' and there was a sense of fatalism about their condition, and a belief that there was little that anyone could do for them. These participants wanted less information about their condition:

*I don't really see there's much they can do really. It's just old age*  
(36;4;19)

*I don't think there's anything anybody could do - it's just old age*  
(19;21;20)

*When you get to my age, there's nothing you can do really*  
(2;13;9)

## Understanding information

Although most participants expressed satisfaction with the information they had been given, participants later admitted that they did not actually *understand* many of the explanations given:

*Well no, to be honest, I only caught so much of what he was saying.*  
(16;4;12)

*I'm not sure I got it all, I think what he was saying was....*  
(8; 33;9)

One of the explanations given for this was that the language that was used was too technical. For example, several participants felt that they did not have the knowledge to understand complex medical matters:

*I just leave it to them. I don't understand about medical stuff*  
(4, 32, 20)

Some felt that detailed medical information about technical aspects of their treatment was actually unnecessary, and again reasons given for this included the fact that they felt it was too specialised an area for them to fully understand,

especially at the time of a diagnosis when it was particularly difficult to cope with and actually caused more anxiety:

*... they told me that I only had 50% of one kidney working, and there were problems but you can live with only one. ... all these numbers were going round in my head, and it wasn't 'til long afterwards when my niece said to me "You realise you've got two, Auntie"*

(9; 33;2)

Participants were hungry for information. They all had many questions still outstanding, and looked to the interviewer as a source of information. For example, this participant was uncertain as to what she might expect in the future, and in the absence of any firm information to inform her, took a negative view:

*..and I'm not as good walking uphill now. I can't get my breath. That's not **normal** is it? Do you know? Do you know about it? It's not right is it? ... eee, I just don't know what's going to happen with this chest of mine, ... I'm only going to get more ... bad now, aren't I?*

(30; 25;4)

This participant seemed to using her perception of 'normal' in order to make comparisons. In the absence of knowing what was 'normal' she found this difficult to do.

## **The role of written information in coping**

Much of the written material that participants had received, had been linked to a specific condition (such as stroke or arthritis), or a particular service (such as the day hospital or CT scanning). On the whole they seemed to find this information helpful in answering any initial questions which they might have had:

*Yes, we got one of those little pamphlets, and that was quite good, wasn't it, we thought ... it had in all about what it was, and that, which was good 'cos there's so much you need to get when you're first there*

(27; 26;19)



Bury (1987) emphasises that patient education material ought to be up to date, accurate and contain what the patients need and want to know (Arthur, 1995), although methods by which to establish this, given the diversity of needs, are unclear. Others observe that patients want to know more about their illness, reasons for and results of investigation, treatments and prognosis (Donovan and Blake, 1992; Kay and Punchak, 1988). However, again the type and amount of information required varied. This seemed to be dependent on numerous factors, including, the condition, the stage in the trajectory, previous knowledge, and their relationship with health professionals.

Some participants had received written information about planned investigations from their local hospital, and comments about this varied considerably. This information, however, usually focused on *process matters*, such as investigations or procedures, rather than focusing on any expected outcome:

*They were very good, yes, very good. They told me what I was in for, what I needed to take with me, that kind of thing, yes*

(18; 2;9)

Either it was perceived to be reassuring and informative, or unhelpful and inaccurate:

*I was a bit concerned about the dizziness, yes, that bothered me, but they said that it was a, you know, normal and that the scan was, what's the word ... routine, yes, and it said what would be happening and what I would need to take with me, so that made me a feel a bit better about going through with it*

(2; 4;8) )

*I got a leaflet from the clinic (goes to dresser and gets leaflet) - you can have a look for yourself. It tells you down here when you need to go and what you need to take, which is helpful, I thought, but it didn't tell us that it would be so uncomfortable and really quite painful*

(9;9;5)

One participant actually felt that she had received more information before her test results (for breast cancer) had been confirmed, than she actually wanted:

*I reckon I got more information about it before I got them ... and I'd rather not have had it ...*  
(4, 32,7)

Some participants, when asked, expressed a preference for written information explaining the investigation, others said that they preferred talking to the doctors directly:

*I like to get something like this (leaflet) in my hand, 'cos then I can look through see, and look things up and that. I like to take me time over it*  
(28; 5; 6)

*He's (GP) lovely, he's so special and he really explains things well, just how you understand, you know, he seems to know what I will understand and says it in a way that I understand. I mean, I'm not stupid, but sometimes it's hard to know what's going on, don't you find?*  
(29; 8;7)

## Relationship with health professionals

The relationships which developed between participants and their carers and health care professionals were strongly influenced by the former's perceptions of the latter's approachability and reliability. The importance of these relationships was indicated by the many comments, both positive and negative, made by participants. Indeed, one of the most important issues emerging from the interviews was the need to identify professionals in whom they felt extremely confident, which in turn increased their confidence in coping.

### The general practitioner

When symptoms persisted or became more severe, they approached a familiar health professional (usually their GP), for explanation and reassurance about specific problems or anxieties:

*I got straight on to him (GP) and told him about the headaches, and the feeling sick, and he said that he thought I most likely had a virus of some sort, and I was so much better, knowing it wasn't anything....more serious*  
(4, 33,4)

*before I did anything, I went up and explained to him (GP) what it was all about, and he said that he didn't think there was anything wrong but he was going to send me (to hospital) for more tests*  
(14, 17,3)

The GP was the first health care professional that participants usually contacted, and was the health professional who they felt they had the most contact with, both in terms of regularity and of total contacts. Participants' clearly had different relationships with their GP's and this reflected on how much they valued their input. This relationship seemed largely to depend on how approachable the GP was:

*If I ever have any problems with it, I just give the {surgery} a ring...  
..they're all pretty good there, and someone comes out to see me...usually quite quickly*  
(3; 6; 9)

*Oh, he's lovely....he always makes time to visit, and I feel I could ask him ..about anything*  
(2; 17;4)

*When I get them back [results] I take them to see Dr \*\*\*\*\*, she's a lady doctor, I've been going to her since she started now, so I feel I know her very well and she's very very good to me. We all think a lot of her*  
(9; 15;12)

Participants who considered that they had a good relationship with their GP also referred to the fact that they considered them a source of professional support, which they valued. A good relationship with the GP also meant that participants felt more secure, which helped them cope with uncertainties of their condition, or living alone:



*He's given me a lot of chivvying up,...gives me a lift....and says "now old, son, it's not as bad as all that, is it?" "We'll sort you out, he says, never worry*

*(21,10;4)*

*I know they're at the end of the phone for if I take bad in the night, they're just a ring away*

*(13, 31;33)*

*Sometimes, I get a bit confused, yes, a bit muddled by it all, yes, I ask Dr \*\*\*\*\* , and he puts me right*

*(14,5;27)*

Advice from the GP was important, and they seemed to trust their advice and judgement, which again helped them feel more confident. A professional's willingness to take a person's concerns seriously and the ability of that professional to communicate information at the appropriate level were both qualities which participants valued. Perhaps because of vague symptoms, individual's first approaches to a health professionals were often very tentative. This participant described how she had had recurrent severe headaches :

*We left it a few weeks, we didn't want to bother anyone unnecessarily, and well, everyone gets the odd headache and you get more **as you get older** (my emphasis)...but then, they seemed to get worse. .and so I got the doctor out*

*(21,27;6)*

If their concerns were dismissed as insignificant, they often felt resentful towards the professional and lost confidence in them:

*..being told that there was nothing there...but there was as it turned out, now we've no faith now, no faith at al*

*(11,11,8)*

This account compares with those who commented:

*He listened to what I had to say, and I could tell he was listening,.....and I was pleased...I felt a lot better when I came out.*

*(14, 07;3)*

Those who had faced professional scepticism and subsequent loss of trust in the health professional sometimes delayed pursuing any further problems further:

*We knew something was not right, we knew, cos I know him, I know when he's quiet he's down, it's always the same and I can tell. ... Well, everyone we talked to just seemed to think it was nothing, you know, a bit of acidy inside and that, so we left it at that, didn't we \*\*\*, and hoped it would clear up. We didn't like to bother them again, but we're glad we did now,...I wished we'd gone sooner*

(6, 9;12)

Those who had previous experience of coping with a chronic illness, either on their own or with another person, were more likely to question the professionals competence if their concerns were trivialised and to approach other health professionals until they received satisfactory acknowledgement of their concerns.

This person described the strategy they adopted:

*we could tell this wasn't usual, it wasn't normal you know, it wasn't what usually happened, cos usually it would clear up in a few days provided I took it easy and that ... it was on my chest and it was November, but he [GP] insisted it was nothing to worry about ... and you're making a fuss and that. So, we got in touch with the nurse at the same practice cos our Julie went to school with her, our Julie saw her actually first off and ... eventually saw the doctor again*

(22; 17;9)

But these cases were not common, and these participants described the stress and anxiety that this had caused them, in one case, as worse than worry about the actual symptoms she was worried about:

*you don't like causing havoc and stopping them getting on and that and when I go next you know what if he says summat. It's worse than the bother*

(22;12;15)

A number of (empowered) participants were less satisfied with the service they felt they received from their GPs:

*he was no help at all to be honest*

(24;12;7)

*they never do much, they're not interested*

(13;29;8)

After several unsatisfactory confrontations some talked of by-passing the GP and going straight to the hospital for advice. However, some lacked the confidence to by-pass the GP if they encountered difficulties and were unsure how the system worked, which was very frustrating. These were the people who were most likely to abandon contact with health services altogether, and through frustration, cope alone, with varying degrees of success. Several people made comments and comparisons between primary and secondary care staff, believing the GP and health visitors were not as well informed than the hospital staff and therefore not able to give them detailed information. 'Hospital doctors', by which participants usually meant consultants, were perceived as being the 'specialist' or 'expert', and were perceived as the best person to give information, at least about detailed medical matters:

*I wasn't happy until I got to see the specialist. When I got the letter to see him, I felt better*

(13; 22;19)

Some participants felt that they were unsuccessful in getting answers to their questions about possible treatments, diagnoses and/or prognosis, and as such they felt marginalised by the professional activity of care. Those participants felt that they became observers of the hospitals' management of their own illness:

*If I asked any questions it was a case of 'we've only just come on, we don't know'. I mean they are supposed to have a meeting to find out, when they come on. I know that. No, I couldn't get to know anything. I was disgusted, but even so, it wouldn't have made any difference, they didn't tell anybody much*

(14;4;8)

*They just didn't seem to care, really. I felt as if I was intruding if I asked too much, and when I got my self together to ask, it was like in the films*



*“your condition is satisfactory” - so I mean what does that mean?*

*(24;6;17)*

*When I finally moved up (to another ward) it was lunchtime. They showed us to a ward and we sat in the corner and nobody spoke to us. They were serving the lunches all the time and you couldn't tell who was staff and who was a patient. Anyway, eventually, this man came up to us with this woman and said “she's going to take your particulars down”. Well her attitude. I just thought she was a patient, anyway it turned out she was one of the staff! I couldn't believe it to tell you the truth. We just sat there and sat there and sat there and nobody came and nobody spoke to us. How can you get that?*

*(13;9;19)*

## **Paternalism and trust**

*Well, as I see it the doctors will ask me what they want to know, and my job is to tell them...and then they'll decide what's right for me*

*(32,23;14)*

Some participants seemed happy to defer to professional opinion. They felt that they had only a vague awareness of the nature of the problem and wondered if they were being protected:

*We didn't actually know he had it until quite recently when he was tested about three years ago. The doctors kept telling us not to worry but they were so vague about everything, and you start thinking , well that they're hiding something terrible*

*(13,12;9)*

This demonstrated compliance and an acceptance of the paternalism of the health service. Others echoed her views, focusing on this issue of compliance. Those who recounted that the doctor had discussed issues with them directly, appeared to have greater confidence in the doctors ability to care for them. Some commented on the importance of honesty and frankness in the doctors communication and believed it was this that helped them to gain trust in the health care team:

*he explained everything really well, I was a bit shocked, but I knew they'd look after me and felt better talking things through*  
(9; 14;31)

*She [doctor] explained everything to me clearly, they were wonderful.*  
(33; 26;9)

Being shown diagrams or specific results, for example, X-rays were commented on as being reassuring and appeared to increase their confidence in the doctor:

*they showed me the pictures which was reassuring*  
(17; 15;19)

In contrast, there were those who appeared to have little confidence in the health care team and expressed dissatisfaction about the way that they received the diagnosis, as described by the following accounts:

*They rang me here , and I didn't understand much of what they said, but it was a young doctor, and it came over quite blase. ....And he shouted: I felt like saying, "Look son, I'm not stupid and I'm not bloody deaf either". The way we were told...we just didn't know how big a problem it was or what, we didn't know what it would mean*  
(34; 23;1)

Participants felt that they would be reprimanded if they did not conform and follow unwritten rules about how to behave in such a setting. Although, no such rules existed, some participants did not feel they could question the status quo:

*I was finished by 10.30, and I thought do you think I'll be able to go home now, but they'd organised the bus, the ambulance to take me home and I didn't want to mess up their plans*  
(30;33;13)

Others recounted incidents when they had challenged the way the service was organised, even at the most elementary level:

*I sometimes feel like having a look round, but you can't do that can you? They don't like that. I once got up to go and see a lady I had met once or*

*twice because we always go on the same day she was sitting near the window. And so I got up and they shouted across the room "Now where are you going \*\*\*\*? You just sit still like a good girl". I felt so ashamed, everybody looked.*

(8;7;7)

Tuckett and Williams (1984) question the implicit expectation that general aspects of the doctor-patient relationship influence outcome irrespective of the medical context of what is said and what is decided:

What explanations are given, what is and what is not covered are likely to exert influence. What clinicians do and do not explain needs to be examined in depth before we can start to resolve debates about such matter as the 'best method' for informing, instructing, influencing and convincing patients and whether it is a worthwhile or productive activity (Tuckett and Williams, 1985, p575).

The earlier discussion of illness cognition's identified a major role for information provision in the empowerment of patients, leading to minimisation of uncertainty and greater adjustment to illness. Nevertheless, although most health professionals advocate the notion of 'fully informing patient', the medical literature gives little credence to information provision in health care, except at a basic level.

Ong et al (1995), in a discussion of cancer care, suggest that doctors need to learn to handle their own anxieties about cancer in a way that does not hinder doctor-patient communication. A study performed by Street (1991) reveals that the more questioning and anxious patients received more information than those who asked less and displayed less anxiety. Older patients, for reasons discussed elsewhere, may be reluctant to question and challenge and may mask anxiety. Health professionals may also subconsciously have ageist beliefs about older people which may present difficulties in information sharing. If the difficulties inherent in compliance and satisfaction are to be successfully addressed it is vital that health professionals own values and beliefs on these



topics are fully explored to help inform their communication with patients. There is an emerging psycho-sociological and nursing literature which addresses these issues. Hagenhoff et al (1994) describe a study by nurses which investigated information needs of patients with heart failure and conclude that they need considerable education to enable them to provide effective self-care. They also highlight the initial period of hospitalisation as a window of opportunity for patient education about medication, risk factors and levels of activities, although whether this is an appropriate time or setting to do this is not proven. Nevertheless, although nurses used these opportunities to provide information, they acknowledge that this strategy was not informed by empirical evidence of patients' perceived learning needs and was a nursing rather than a multidisciplinary initiative.

## **Evaluating clinical procedures and attributing change**

Without appropriate information, people were left to make their own judgements about their condition, and about expected change. The parameters were set according to their previous experiences of illness and knowledge of their situation. In terms of evaluating clinical services and procedures and attributing change - two key characteristics of person-centred outcomes - the empowered group of individuals seem deserve greater discussion. This was a group who could articulate their needs and their contribution to developing approaches to person-centred outcomes for older people in general deserves further recognition.

### ***Empowered individuals***

Four participants concluded that their decline in appearance and their functional ability was not due to any real decline in *health but to* a lack of health care intervention. They felt that, in view of the care they had received over a period of

weeks, that it was the type and standard of care itself that was responsible for their condition and for this outcome. For example, complaints were made that at out-patients, as a patient at the day hospital, and as an in-patient, that there was a lack of stimulation which they linked to motivation and that staff actually restricted mobility:

*You feel like you've got to sit there really, and not say anything. It's very boring*

(29;32;9)

Complaints were also made that when in hospital they were taken in a wheelchair:

*They had me in a chair, and I went to the x ray in it and that and I thought am I ever going to get out of this thing?*

(34;5;14)

*mind you, in hospital, I didn't try because I was always in a wheelchair. I think they wheeled me in a wheelchair to the toilet in the wheelchair, so I didn't get much better if practice makes perfect*

(30; 4;19)

Participants here were making a link between the intervention and an outcome. They were also implicitly suggesting that their own motivation might be a factor in influencing outcome. From their accounts, a lack of motivation was perceived to result in a negative effect. They made little attempt to exercise, but they clearly felt that if they had been encouraged to be more active, specifically to walk more, then this would have aided a change in their condition.

One participant - Mrs Fitzgerald - lived with her husband, and had a large family network living locally. On discharge from hospital following a hip fracture, she went to the day hospital twice a week for rehabilitation, mainly physiotherapy. She described how she had talked this over with her family, formulating ideas and sounding out her friends and family about both what she might expect and what course of action to take. Together, they seem to have formulated their own

ideas about what would be necessary to 'regain her strength', as she put it. Mrs Fitzgerald in particular did not look to the clinical setting to provide the answers, preferring to take a more holistic view:

*I don't think they can do much for you, can they? They're very good for some people, but with me, I just needed a bit of sunshine to heal my bones, and plenty of fresh air and as much exercise to get moving as I can manage. It's bound to take time at our age, you don't heal. When it was fine, I went out with Derek (husband) and the kids (grandchildren) - just taking it steady, ... and it's the sun that I need to get me on the mend*  
(10;44;7)

Her desired and expected outcome was to regain strength in her legs, to help her move about better. However, when questioned what intervention she thought she would need to do this, she identified time as the most important factor, although she did not know how much. Her perceived strength in her legs changed from day to day, and the length of time it took was not particularly important to her, nor was a 'quick recovery':

*No, not really, pet. ...I think we just take each day as it comes, you know. You can't really put a time on it can you? ... and I'm a lot better than I was a few months back, before I went in (to hospital for the operation)*  
(10;45;7)

She felt that the hip replacement operation had been a technical success - a positive outcome. In this respect she linked the operation and a new hip- the intervention - to her greater ease in moving around and reduced pain. However, she stressed that it was her family support network which she perceived gave her recovery the most *meaning*. Her desired outcome was not merely to *function*, but to be an integral part of her family group. This group gave her a sense of confidence and contextualised her experience in that whatever the outcome in terms of her regaining a previous level of mobility, for example, she would cope with any outcome or change, as she felt surrounded by people who would love,



support and care for her, and who gave her security, a sense of belonging, of purpose which she valued above her own 'health' status:

*I'm very lucky to have Derek and the family local. We're always there for each other, and I know that even if I was ever house bound they'd be there, you know, come and cheer me up and that and we'd be all right. I think that's what's important in the long run*

(10; 8;35)

*I look forward to going out with the bairns and that you know, just being able to get in the car and that*

(10; 9;3)

Mrs Fitzgerald comfortably made the transition from being a 'patient' in hospital to returning to her former life-style, albeit with slight allowances and adaptations for her physical condition, such as not being able to stand for long periods of time. She retained a positive sense of self and a sense of belonging within her family unit, which seemed fundamental to how she evaluated change.

## **Expectations of health care**

The differences between participants were complex and depended upon a wide range of factors, including levels of family support, the severity of illness and stage on the illness trajectory, how well the person felt at the time of the interview, their experience of health and social services and whether these experiences were perceived to have been positive or negative.

In contrast to Mrs Fitzgerald, some people felt that on discharge from hospital they occupied a kind of 'twilight' status, in that they were no longer a 'patient', but at the same time were treated like one. For some this was problematic because they had ceased to be passive and were providing for themselves again, and saw no reason to still be a 'patient'. As information was hard to come by and even basic therapies were not in evidence they decided to take their 'rehabilitation' into their own hands and provide other solutions and other explanations. This again

is a different emphasis and interpretation of independence, and also illustrates decision-making skills and recognising and exercising choice. The fact that they were willing to search for other options, suggests that they felt that their needs were not necessarily being met by existing services. They were consciously looking for an intervention as such which they perceived would bring about change, and also implicit in this was the judgement that without an intervention as such, either change would not be forthcoming or would be a slower process. They made no criticism of staff, preferring to give the view that there were many people who were 'worse off than them' and that they recognised that staff were busy:

*I just take myself out for a bit of fresh air. They haven't got time to do it, although I like a bit chat. I suppose there just aren't enough of them*  
(46; 15;29)

*... but they can't do that, of course, there aren't enough staff. I think there was one or two people in charge, but they're too busy, you see*  
(3; 37;1)

When asked to specify what they would like to see happen, however, they were still unable to do so and seemed confused by the concept. They felt they did not have enough knowledge about the structure of health and social care to make informed judgements, reinforcing this theme from the focus group discussions. They floundered with a lack of comparable situations and could only refer to others they knew who had been in a similar situation:

*Why, this fella from the club was in June gone and when he came out he went back to the hospital daily, every day, like, they come and took him, and why, I don't know what he had done like, you know, but, er, he went up there, and they must have er been doing something all that time, but er nobody's said anything to me, like, not as now anyhow.*  
(34; 12;4)

Mrs Dawson reached this stage of believing that her best interests were not being served in hospital. This is conceptually different from merely 'wanting to go

home'; i.e. from wanting to be in familiar surroundings and not in hospital. Mrs Dawson had consciously made the choice that she felt she *would make progress* at home and said that she felt it was difficult to judge her progress when she was in hospital, as the surroundings were artificial:

*I think they've done as much as they can for me. They've been wonderful. Really wonderful....but now, now I think it's about time I was home, I feel once I'm back home I know how I'm doing, you know, once I'm back in my own routine, you can tell how you are more, you can tell how you're going to be*

(43; 39;3)

At this stage she did not define what this progress would entail; for example, whether she meant progress following her heart attack or whether she was speaking in more general terms. She later said that a factor underlying this desire to return home as quickly as possible was a fear that if she did not return home soon, she might not be able to:

*Well, at my age, well....I don't want to go into a Home, I know I'll have to in the end, but I want to stay at home. I don't want to go in one of them*

(46; 49;7)

While individual mobility and functioning were important to her, the wider social and economic consequences of not 'improving' seemed to be a very real motivation.

In contrast, other participants recalled negative experiences. Another participant described her experiences when she had been caring for her husband, who had since died. She had decided to effect her husband's discharge. In taking this decision she had discussed the idea with close family members and health professionals, and also with her husband, as to whether he wanted 'to come home':

*he said "I feel really rotten". So I said "oh blow it, I'll take you out". I brought him out because he was getting fed up. I was getting fed up. In the end you have to go with what's in here (points to her heart). When I*



*saw the state of him, I thought I can't leave him in here, he was just going down and down and down. So I said to the nurse: "what about me having him home?" And he said, "oh no, you couldn't look after him, you couldn't cope with this*

(27; 18;6)

Appeals to higher authorities, such as the consultant geriatrician, had brought the same response:

*... "do you realise what you're taking on?" "Well, yes", I said "but I can't leave him here any longer". In the meantime there was no communication between anyone. Anyway, my daughter persuaded me to ring up and get an appointment and so I went in to see Dr Anderson and I said "What do you think about Jim?" I said and he said "Well, what do you think", you see. I said "I think he's ready to come home". And I went in ready for battle if necessary. After that I knew I was on my own, there was no question in my mind of him ever going back in there ever*

(26; 19;3)

Faced with the paternalism and reluctance of health care professionals to discharge her husband, her decision to take responsibility for her husband's care at home had not been easy. However, she did perceive that she had a choice. When questioned about the process she had gone through to make this decision, it seemed that her decision had been based on her perception of her husband's 'quality of life', in terms of what he needed to 'lift his spirits', rather than in purely physical terms. She could not consciously perceive an 'outcome' as such, her actions seem to have been based on instinct rather than any conscious decision-making process. She said that she instinctively felt that her husband's quality of life would deteriorate (negative change) if she did not take him home:

*He would go down hill. They weren't giving him what he needed. I could see it in the lines in his face - always when he's anxious he gets these deep grooves down the side of his cheek here, always .... And well, he was thin, too thin, but I could see they were there. Now nobody else could see them, but I'm his wife*

(26;20;4)

She believed that little attempt was made to teach her the complicated procedures that were needed to keep her husband alive, because she discharged him against medical advice. Obviously, without discussing the situation with the others involved, only this individual's view is discussed. The severity of his stroke meant that tube feeds, catheter care, limb exercises, and pressure sore care were required hourly. She received a 'days practice' to prepare her for his care at home:

*then when I took him home, I'd only had him back for three days and he went back in on the Friday night, we had the emergency doctor and he said he had a urinary tract infection. They sent him back in, apparently he was dehydrated. They had told me to give him 50ml of water after each feed to wash the feed down through, so of course that was all he was getting. Anyway, they decided he was dehydrated*

(26; 21;7)

These initial experiences formed the basis for all her subsequent views of the health services, both community and hospital based. Not only was her husband reluctant to become a patient again, and this participant was adverse to allowing her husband to go back into hospital, but there was also a belief that rejection of these services subsequently invited, and seemed to justify, a poor home-care service:

*you could see that they were offended that we wanted him home. And there was no help after that. I think they thought "get on with it then"*

(26; 21;19)

These feelings are linked to a feeling of disempowerment, but also a feeling that services and the approach of health professionals can appear inflexible and not person-centred. Value judgements are made on behalf of both patients and carers. This participant's experiences also highlight the purely 'physical' focus that services and health professionals sometimes may take. This highlights issues about resources and the fact that it was perceived that the resources were not available to support this participant's husband in the community, and that



therefore she was behaving irresponsibly by refusing to conform and accept treatment from the hospital. These events had happened four years previously. Mrs Webb did think regularly about what would happen if she ever needed to go to this particular hospital:

*I have thought a lot about it, I have thought what I would do if ever I take bad. But I think I'd do the same again - I think only **you** know what you need. They're very good, tremendous up to a point and then I think only **you** know what's best for **you**. They don't know that do they, how can they? They've only known you days*

(26; 27;8)

This illustrates a willingness to take responsibility for the direction of care, and ultimately for the outcome. This participant wanted choice, but felt that there was only a limited range of options available to her and that she was not fully supported when she made her choice, illustrating a need for improving communication between professionals and 'users'.

Mr Henry had medical advice, but as the information and subsequent treatment that he had been given, did not match his own 'diagnosis' and accounts of what was happening to him, he preferred to formulate his own treatment. The empowered participants were more articulate about forming opinions about what they both *expected* to happen, and what outcomes they would *like* to happen. Mr Henry was 87. He was a miner in Durham for forty five years, and was now suffering from advanced heart failure, severe arthritis in his knees (*from years of cricket; 39;4; 9*), and walked with a pronounced limp as his foot had been crushed in a work-related accident some years before he retired. He described his recent experience at the day hospital:

*I got these tablets for my breathing from the doctor, and he said take two of these a day and come back to me in six weeks. So I took them, two a day like he said, and the weren't having any effect, I was breathing just as bad as when I didn't have them, in fact I would say that I even got worse. So, I stopped taking them, and went on to these others that my wife has,*



*and now they seemed to do the trick see. I found that I could get out to get my paper most days without having to stop too often to get me breath back, so that was good "*

*... I go round the corner there, to the newsagent, and they keep me a gazette back for the sport, I like the football, it's just round the corner, but it felt like a canny hike when me breathing got bad. But I found that I could get round to number seven before I had to stop, and then few days time, I got to number thirteen which is a bit further, you see. It's my way of seeing what I'm like, a little game I play with myself*

(39; 20; 16)

In this way he was designing his own methods of monitoring progress over a period of time and was self-monitoring any change in his condition. He seemed puzzled at the point of asking how long this process of change took, but when pushed felt that he made progress over two or three months. However, within this he highlighted the fact that he had '*good and bad days*'; some days he had to stay in bed all day, some days he felt he had '*a great deal more pep*' (39 12; 5). He felt that the tablets he was taking somehow helped his heart condition - linking the intervention to change in his condition, with a positive outcome for him in that he was able to make the visit to the local shop. However, he had not told either his own GP or the hospital staff at recent visits to both, that he was no longer taking the tablets prescribed, but selected his wife's prescribed tablets, despite the fact he collected a repeat prescription! His wife had a totally different heart condition, and so any change in Mr Henry's clinical condition seems to have been down to more coincidence than an expected change. He gave several different reasons for his decision to change tablets:

*[Did you mention this to your doctor] No, no [why not?]. Well, (pause) I didn't want to disappoint him ... I thought he might be angry ... I didn't want to upset him, you know it'd be like telling him that he got it wrong ...*

(39 24;5)

He identified a way of taking the information that the doctor and others had given him about his condition, so that he felt that he knew what was causing the problem, and what his limitations were. He felt that he knew what effect the

tablets would have, and as he could feel positive results from taking the other tablets and that these were reflected in his ability to go and get the newspaper from the local shop without undue difficulty, his own defined parameters for 'measuring change':

*The doctor seemed to think that the tablets would improve my breathing, and that gave me a bit of hope, like. I was feeling pretty down beforehand like, thinking it was summat serious, you know, but when he said that he thought these would clear things up a bit, I kind of got a bit o hope up like and tried a bit harder and that*

(39 12;9)

Again, he implied that he considered the fact that his confidence was raised, that he was reassured and his own motivation and effort were significant factors in contributing to a change, not necessarily in just his *clinical* condition, but in how he felt about himself and his sense of control over his situation. These were important outcomes to him. Participants found it easier to conceptualise practical services rather than more abstract personal definitions of outcome. One participant suggested that it was because of the structure of the provision of services that many problems still occurred:

*Well, all they could offer me and Billy was meals, twice a week, and someone in to help clean and tidy and that, and well, I can do all that, it's not really what we'd need*

(15; 7; 18)

But many participants were not able to conceptualise *alternatives*, or articulate what they would need and in what form. They were not able to think through any gaps, or if any changes needed making. The most common response was to accepted what was there without question, which was linked to the public accounts of resources and value of older people in general. These participants had clearly thought the issues through, either as a result of a past event which had meant they had had to think about what they, or the person they cared for



wanted, or in that they were very unhappy with their present situation. However, they felt they lacked both the opportunity and the 'know how' (4;15;8) to discuss issues with professionals.

### ***Reluctant collaborators and dominated individuals***

In contrast to the empowered individuals, these participants were more reluctant to have to make any decisions or to participate in care. One participant explained how he had had a stroke, and was admitted to hospital:

*When I was first ill, I started with the shivers, and then started falling. One night I went into the bathroom , and thud, I was on the floor. Anyway, the ambulance came and I was taken in and they reckoned I'd had a stroke*

(40;4;18)

This participant felt that the hospital was the best place for him, as expert help would be on hand, should he deteriorate. He had no complaints or comments about the treatment and care that he had received. It was not possible to tell whether this was because he felt unable to judge, or to accept the possible consequences of making a judgement, about the standards of care provided. He chose to defer to professional opinion. With such participants it was difficult to gauge what their expectations of services were. Participants could also appear to have accepted what they had been told by professionals at face-value, and made little attempt to reflect on what was said. Most appeared very satisfied with the explanations that they had been given, or when they had been referred to another service, which could relate to low expectations rather than real satisfaction, and were reluctant to criticise.

*... he said that he'd only seen about ten in his whole time as a doctor and the fact that they can do so much these days was a comfort*

(36, 17,3)



For a large group of patients, attending the day hospital or any other clinic was considered to be routine, and they expressed little expectation that there could be any change or improvement in their condition as a result of attendance. Participants in this group appeared to be relatively content with the status quo. They expected little and did not question the treatment, or services, that they received. Consequently, even in situations where participants felt that they did not have enough information and explanation, they did not press the issue or even sometimes consider contacting professionals, preferring to form own explanations, in absence of formal ones. The concept of reflexivity is significant in that on occasions when the participant was interviewed twice, on the second visit, participants displayed greater anxiety, following the discussions:

*it's not something that I've ever thought about really...But I've been thinking about what we were saying when you were here last....I've been thinking about it all, and I was talking about you to my daughter when she was round...and I find it very hard, ...there's just so much going on, and you decide on something and think yes that's it, but then you think again, and think no what about this and that, what about family and that, and I get so muddled I can't tell you.*

(16;6;4)

*I don't know what is possible. I don't know what to do. I don't know what is available to help me*

(8;33;9)

*I don't know what is realistic. I don't want any extra hassle. I just want to be left in peace.*

(17;9;31)

## **The concept of achievement**

*When people are working, they must look at us oldies and think "what a life, sitting around all day" - they don't realise that we don't, or some of us don't we don't want to be sitting around all day, I've never liked it, never have, never will, and I don't like reading, never have, never will, but it's the thing everyone says "why don't you settle down with a good book - I love a good book" Well I don't! I want to be out there*

(1; 13;4)

The term 'achievement' commonly implies *success* and also an *end, a result or a level* of performance and to acquire by effort. Achievement is a generic concept that can cover a tremendous range of human activities. Firstly, achievement could be a concept which people talk of in terms of standing out from the majority, (for example, being prime minister), of distinction or performing some well-defined task better than competitors, (e.g. winning an Olympic medal). Secondly, achievements are perceived as being as a result of having certain skills or talents, and where only a small percentage are considered to have these qualities. Achievement is also associated with motivational characteristics, such as effort, persistence, drive and determination. Sometimes, an activity is labelled an achievement even when it requires far more motivation than ability or skill. This is true of many of the achievements in the Guinness Book of Records - for example, the person who holds the record for the number of days spent sitting in a bath of baked beans is earning admiration for persistence rather than talent. But it is achievements that seem to require both *ability* and *effort* that elicit the most widespread and profound esteem (Coopersmith, 1965). The concept of achievement, then, is value-laden, and the word achievement is usually assigned to behaviours or products that have 'positive social value'. Not only may these value judgements vary from culture to culture, but also from individual to individual. The term 'achievement', therefore, is interpreted differently by individuals, depending on their sociocultural perspective and experiences, and is influenced by biological, physiological, psychological and sociological processes. In this final section of the analysis, the meaning the term 'achievement' to some participants and the implicit link to the concept of outcome is discussed.

### ***Finding meaning from achievement***

The discussions demonstrated great diversity in terms of personal resources, lifestyles and experiences. Although participants did not talk in terms of what

they or their family had 'achieved', they did refer to important events or markers in their lives which they felt were significant in signifying a certain level of achievement and were important part of their life biography. This was personally defined. Some participants, for example, both male and female, focused on their jobs or careers:

*I was a head mistress for thirty years at \*\*\*\* girls school ... I don't think I was strict, no, but the girls were very disciplined, and we had a reputation for being strict, which I think I liked - it gave the right message to parents who wanted their girls to get a good education. We had very high standards*

(13, 7, 13)

*I was foreman at \*\*\*\*\* when I retired, worked there forty year near on, I worked my way up the ladder from tea boy, I worked hard and got the rewards*

(12;7;7)

### ***The perceived effect of age on achievement***

Ageist attitudes in society clearly influenced some participants perception of the concept of achievement. Successful people who are older are seen as the exceptions, not the norm. Whatever their past perceived achievements or experiences, all participants were linked by a common feeling that now they were older there was little to achieve. This was in two ways: some participants felt they had nothing to achieve because they were *old*, they were incapable of achieving anything, and talked of being '*past it*' etc.:

*When you get to my age, you've done all you're going to do*

(15;5;15)

*When you get to this age, you're not going to get any better, are you, its down hill from here*

(31;5;19)

By contrast, others were conceptually different in that they felt they had nothing to achieve because they had nothing to *prove* and seemed more content with how they were. This was perceived differently, however, in that participants



talked about feeling that they were happy with who they are, and what they were and a positive tone to when they talked about what they had achieved in life, it was with a sense of pride. For example, Mr Bentley talked with pride about his career, but his pride was tinged with defensive tone:

*I've done it all - you get past it, when you get on in years, you've got nothing left to prove*

(14;6;8)

This idea of 'proving' something was followed up with Mr Bentley, who went on to explain:

*When you're younger, you've got something to prove, you're like you, full of life, plenty of 'go' in you, but when you get on a bit, you see that you're all right as you are and if there's folk who don't like it, well, that's their problem*

(14;7;9)

Another participant - Mr Palmer - explained his feelings about achievement. He felt that he had lived a fulfilling life in that he had a happy marriage and family life which was very important to him, and valued that he perceived that he had met his responsibilities in all spheres of life. He did not want to see this invalidated by a sense of 'failure' now:

*I don't like to think that I'd be seen as a failure if I couldn't do what I said or what they said to do . I've always worked hard, I've never complained about that, I've worked hard for my family and I'm proud of that and no one can take that away, no-one should be allowed to*

(16;19;3)

Another participant referred to his reluctance to attempt to achieve any 'goals' that he or other may set, because of past failures to achieve and a fear of failure. He felt threatened by the introduction of this concept:

*I think I'm a bit, you know, well, I suppose scared, I suppose, you know. It's a horrible feeling when you know that you can't do anything [What do you mean when you say that, Arthur?]. Well you're only human, so if you know you can't do it, you stop trying really, you know*

(15;5;19)

He linked his lack of motivation to failure to see results in his condition after months of trying. But the achievement potential of individuals may not necessarily decline just because the observed levels of achievement may appear to fall off. Enthusiasm may diminish if an individual perceives that they are less likely to reap the benefits. But this might be reversed if an individual perceives an altered cost-benefit ratio. A common assumption in the medical literature for people working with older people is that 'with older frail age group, they are limited in what they can be expected to achieve' (Brocklehurst, 1991). This is a value judgement, and in tune with the *professionals view*, what they would like them to achieve in terms of restoring to more 'normal' ability. From the persons point of view, what they *want* to achieve and what they are *able* to and *do* achieve is personal, and individually defined.

The concept of achievement is important as it is either *implicit* (in terms of 'can you make a cup of tea'? type questions) or *explicit* ('what do you want to achieve'?) in many commonly-used assessment instruments and measures of outcome (Rockwood and Stolle, 1993). In Goal Attainment Scaling, developed by Rockwood and Stolle (Rockwood *et al.* 1993; Stolle *et al.* 1992; Rockwood and Stolle, 1997) one of the questions asked of people by the members of the multidisciplinary team is in fact just that: 'What do you want to achieve?' This appears a simple question - it is assumed that we all understand why it is being asked and what is meant by 'achieve'. But on closer examination, the concept of achievement is more complex, with varying connotations and emphasis, depending on how the individual interprets it. Understanding more about how people interpret this concept is important in developing approaches to incorporating peoples wishes and desires in patient-centred care. There is some evidence that patients have physical, emotional or social agendas when they consult health professionals, but evidence that doctors are less comfortable with

emotional and social agendas (Butler, 1992). Also, patient-initiated physical agendas in response to the question 'what can I do for you?' or 'what's the problem?' suggests that patients perceive a physical agenda as the most acceptable way to commence the interview, perhaps 'legitimising' their presence in the surgery.

Outcome measures seek to monitor changes, perhaps preferably improvements, as a result of health care interventions. For example, in terms of functional ability, if the patient's functioning improves, an implicit assumption is that the patient and the multidisciplinary team have achieved this improvement through a range of potential paths, which may include a improvements in muscle strength as a result of physiotherapy or a new walking aid. However, again, what the professional considers an 'achievement' may differ from the individual that they are working with. Older people who do not necessarily *achieve* in terms of gaining on standard measurement scales, are perceived as a 'a failure' of health services.

So, in terms of merely asking someone outright what they would hope to achieve' in a health care setting, is likely to illicit a response from some people, which is the public response, not necessarily the answer which is closest to their private account, and the one that they are most keen to achieve. These are private views, and not readily shared, not just because the person is unwilling to confide in a particular individual, but also, because the person themselves may not have consciously conceptualised it, or may not have the vocabulary with which to articulate their views.

Two participants in particular were keen to talk about this area. As the following quotes illustrate, their attitudes were firmly grounded in their social context and styled by their beliefs in a lack of services and mechanisms to help them. They



did have goals, they did have expectations, but were doubtful that the existing services that they knew about could help them meet them. Participants had identified barriers to them achieving their goals. One factor particularly that emerged was that goals were *ongoing*. The goals that individuals set themselves were experienced on a daily basis, and whilst they indicated progress to the individual, they did not think in terms of weeks or months, but more of a longer process:

*I don't think I think about a time point, I think more about taking it day by day, and so I don't think lets see how I am in a months time, no, because what would that mean, I just think see how you are from one day to the next*

(30; 44;9)

## Summary

Little evidence exists from collaborative studies about the relationship between information provision and outcomes. Although each of these features of health care have been independently investigated, they are mutually inclusive and require simultaneous scrutiny, to improve patient satisfaction with health care, to inform the future training of health professionals, to develop communication between health professionals, processes of empowerment and participation and to develop approaches to person centred outcome measures. There has been significant shift towards a greater psychological understanding of coping with chronic illness. Unfortunately, the evidence indicates that this enlightenment has not greatly improved professional-patient communication. By considering the empirical evidence of health cognition's of both patients and professionals it transpires that there is a dearth of information about professionals own health beliefs and attitudes and how these may impinge upon their attitudes towards and communication with patients. Patients' views on information needs, perhaps especially older people as a groups' views, are also under represented in the

medical literature. This imbalance needs to be addressed using qualitative methods to establish the reasons behind them. Professionals are reported to value the ideal of an 'informed' patient, but display reluctance to attach equal status to information provision, diagnosis, treatment and care decisions. This indicates a need for further in depth investigation of these concepts, including the current status of information provision in chronic illness, from the patients perspective, along with issues surrounding communication, participation, decision-making, empowerment, and satisfaction.

Information and receiving support was significant in influencing participant's perceived ability to understand and cope with their overall situation. It has been suggested that up to 94% of patients would like to know as much as possible about their condition, even though the news may not always be good (Fallowfield, 1994). These studies refer to studies when patients were discussing information needs relating to a specific condition, such as cancer, and the processes around the diagnosis and treatment of the disease. Participants in this study did discuss such specific conditions and events, usually relating to the conditions which they were currently receiving treatment for, or coping with the effects of, but for some the initial diagnosis was many years ago, and so information needs and attitudes to information for these participants had altered over time, as they adapted and amassed more experience and knowledge of living with chronic illness. For this reason, some participants discussed a range of specific events drawing on their own experience , whilst others considered their views in more abstract terms.

'Meaning' in chronic illness has been variously described and Bury (1991) distinguishes two types; 'consequence' leading to the development of strategies for minimising the effect of disruptive symptoms on every day life and 'significance' which proposes that the symbolic, societal significance of different conditions will affect adaptation. Whilst illnesses may be stereotyped and

stigmatising, for example, 'arthritis' or 'diabetics' or 'epileptics' (Jacoby, 1994), the illness meaning for the individual with chronic illness often changes at different life stages (Johnston and Marteau, 1990) and is an ongoing process. Lazarus (1961) uses the analogy of the learner driver needing appropriate knowledge and skills to achieve complete command and mastery of the vehicle. In the early stages of learning, command of the vehicle is usually shaky and anxiety high. With increased knowledge and consequently the belief that he/she is in command, once frightening situations can be met with security. Applying this analogy to illness, he suggests that the more knowledge and control the patient believes he/she has, the less vulnerable and uncertain he/she will be. This approach has been reinforced by other authors (Mast, 1995; Nolan and Nolan, 1995). Personal resources such as skills, knowledge, experience, history of success in previous crises and positive health beliefs all contribute to a sense of security and anxiety reduction.

Participants in this study tended to contextualise their situation and add meaning to their experience. They felt that they lacked the mechanisms and control over the process of information; that health professionals time was very limited and that they lacked the opportunity to ask. Many felt confused by the different health professionals. They felt they lacked knowledge about what to ask and how to ask it, and were uncomfortable with many terms, with language and communication. Many also described problems with having to make decisions at a time when they felt too ill to make them. This mirrors findings from the focus groups discussions.

Clearly, people found it difficult to articulate goals, achievements. Because of the link to uncertainty in chronic illness, asking people, who were previously unused to discussing such issues, to suddenly prioritise and consider the immediate future in such a structured and unfamiliar way was clearly not



understood. However, people were more comfortable with discussing other peoples' situations and reflecting with hindsight on their own, rather than being able to discuss the present problems. Within this, people were more comfortable with discussing relationships and aspirations to do more social activities than they were discussing their medical care, which was accompanied by considerable feelings of insecurity and caused extensive anxiety.

## Chapter 16

### Discussion

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society creates the framework of institutions and rules within which the general problems of the elderly emerge, and indeed, are manufactured. Decisions are being taken everyday in the management of the economy and maintenance and development of social institutions which govern the position which the elderly occupy in national life and these who contribute powerfully to the public consciousness of different meanings of ageing and old age

(Townsend, 1981, p9)

The rationale for this study was a need to bring a social science perspective to approaches for examining outcome. To date this field has largely been dominated by clinicians and the biomedical model of impairment, disability and handicap. Qualitative methods (findings from focus groups informed later focus interviews with individuals) were used to establish and explore the views of older people about a range of issues linked to conceptualising outcome, including participating in decisions regarding their health, to examine how older people made judgements, what they valued and prioritised, what their expectations were, how care was experienced and how changes are sustained over time. In this final chapter, it is argued that future best practice for outcome evaluation in health and social care professionals will need to explore the *private* views of older people in greater depth. Institutionalised ageism and structured dependency are major barriers to empowering older people to participate in identifying outcomes. Until these issues are recognised and resolved, more meaningful participation in the identification and method of assessment of outcomes is unlikely. The findings should be of relevance to researchers, to

users of health services and to clinicians working in rehabilitation settings for older people.

## Limitations of the study

This study is the product of three years work by a social scientist whose basic discipline is geography. Prior to embarking on this study, I worked for two years as a research assistant in health services research on an audit of day hospitals for older people. Understanding the context in which outcome measurement has been developed requires sociological and psychological expertise which has evolved throughout the life of the study. Therefore the experience was an extremely valuable training exercise.

The exploratory and small scale nature of this study, combined with the complexity of some of the issues, limits the extent to which these findings are presented as definitive and conclusive. Among four men interviewed the distinction between public and private accounts of care were not apparent. A larger and more detailed study may be required to assess whether men conceptualise outcome and talk about care-giving in different ways.

A particular limitation of the study was that there was not a young group of people for comparison to try and explore if these findings are applicable to *all* people, or to other groups as well as older individuals. Also health professionals perspectives were not explored. Therefore, the question of whether the issues identified for older people are any different to other people and if there is a case for developing approaches to measurement specifically for them deserves further exploration. Many share the pressures and experiences of all people with chronic illness. However, older people do have additional jeopardy because of ageist stereotypes.



## Limitations to the current practice in outcome measurement

It is sometimes argued that the field of outcome measurement is a field which lacks a rigorous underpinning theory and precise definitions that flow from theory (Ventegodt, 1996). There is some basis for this criticism; much of the work in this area stems from the very applied and pragmatic problem solving, rather than from an explicit theoretical framework (Fitzpatrick *et al.* 1998). However, others would argue that there is a theoretical foundation in the form of psychometric methodology which has provided the basis for most patient-based outcome measures (Nunnally and Bernstein, 1994). This 'scientifically rigorous field' is concerned with the science of assessing measurement characteristics of scales and involves properties as validity, reliability and responsiveness (Hays *et al.* 1993). Similarly, economic contributions to this field have also a broad theoretical literature on which to draw evidence such as decision-theory (Torrance, 1987; Drummond *et al.* 1987; Fitzpatrick *et al.* 1998).

However, these normative approaches do not always even live up to their own standards. Recent texts on selecting and using outcome measures (Bowling, 1992; Fitzpatrick *et al.* 1998; Bowling, 1995) stress the fundamental requirements which patient-based outcome measures must meet, including reliability, validity, responsiveness, acceptability and feasibility, but there is no language or framework for identifying what these mean to older people or how they may be discussed. Also, for a measure to be truly 'person-centred' two additional properties, the appropriateness to the person and interpretability of the instrument, are important. Yet these are less likely to appear on checklists for selecting outcome measures (Fitzpatrick *et al.* 1998). Indeed, the issues of the interpretability of scores derived from existing scales and measurements has only recently begun to receive attention in the literature on patient-based

outcome measures (Fitzpatrick *et al.* 1998). Interpretability is concerned with how *meaningful* the scores of an instrument are to the individual. To date, it is not possible to compare patient-based outcome measures in terms of interpretability, largely because we know little about the person's perspective.

There is now an enormous array of questionnaires and interview schedules that have been developed which are intended to supplement conventional measures of the outcomes of health care by 'direct assessment of matters of most concern to patients' (Fitzpatrick *et al.* 1998). These 'patient-based' measures differ in content, length, form of delivery, measurement properties, and intended purpose, but the main rationale for their development has been to ensure that the patient's views are represented, as it is widely acknowledged that their views may differ from those of researchers or health professionals. It is generally accepted, then, that research needs to assess the outcomes of health care directly from the patient's perspective (Fitzpatrick *et al.* 1998). But exactly what is the 'patient's perspective'? The data from this study illustrates that it is rarely a single entity that can be simply captured, but rather consists of a number of different perspectives, which changes, both over time and between contexts: a personal, individual, dynamic trajectory. This then challenges the basic essential psychometric property of validity.

Traditional approaches to outcome measures have long been criticised for oversimplifying peoples' views, for imposing values and for 'pigeon-holing' responses. By focusing on simply the 'content' or 'what' was raised, for the purposes of moulding the data to fit the standard normative approach and fulfil certain psychometric properties, such approaches over simplify the social world and also risk misunderstanding the way and the extent to which actors classify their behaviours and intentions. It is, then, perhaps not surprising that the validity and reliability of such measures are relatively poor, as they are failing to reflect



the complexity of the form of people's views and how the significance of an event is constructed and reconstructed by individual actors in everyday life. In other words, it is not possible to construct measures which mean the same to all patients at any one time, let alone all patients and health professionals, or all patients over time.

However, despite these problems, it would seem to be the widely accepted view amongst clinicians (Royal College of Physicians and British Geriatric Society, 1992; Fitzpatrick *et al.* 1998) that the way to proceed with the development of this field is to continue to develop new measures or to refine existing ones in line within the dominant positivist paradigm, with increased emphasis on psychometric theory. The value of this paradigm overall, however, remains largely unquestioned by those who use psychometric methods.

Existing approaches to measuring outcomes for older people which use the dominant positivist paradigm are incomplete and inappropriate as they do not take account of the individuality of older people, and of low expectations and lack of information and skills to make decisions. Approaches to measuring outcome in health care settings must include people's own definitions of appropriateness, which informs the evaluation of the impact of the intervention.

## **Summary of key project themes and data**

In coming to an understanding of how older people conceptualise outcome, the distinction is made between public and private accounts. These two types of account reflect the different ways in which older people constructed and talked about their experiences.



## **The focus interview study: the public accounts**

The public accounts reproduce the idea that the way people discussed the issues were grounded in the social and moral obligations associated with ageing.

Obligation is not, however, simply explained in an abstract and normative sense of 'doing ones duty' or as a response to an externally imposed moral imperative.

Feelings of obligation are described as arising from the relationships in which they occur and represent a personal interpretation of the 'right thing to do' in a particular set of circumstances. Reciprocity and conscience are integral to this interpretation of obligation. Being conscious of the reciprocal nature of society, of what had to be given and received, meant that such a stance was the 'right thing to do'. In this way, obligation is viewed, within the public accounts, as personally and inescapably binding.

The public accounts provide the framework for understanding that connections exist between older people and the 'face they may present to strangers'.

However, they give no detailed insight into how these connections are, in practice, generated and sustained. In public accounts, participants justify their view in general terms, the emphasis being on why someone should receive care, rather than why they should be provided with care. As interviewing progressed and more complex situations and context were revealed, these initial accounts, while crucial and relevant, appeared to be simplistic and lacking in explanatory power at an individual level. As the public account invariably came early on in the interviews, they were understood as a reflection of the broader social and cultural assumptions and beliefs about older people, which older people themselves believe.

Problems at a wider societal level relate to the distribution of power, ultimately given finite resources, to who is to determine which needs are met etc, and which objectives are the most important. Policy objectives which 'encourage

independence' may conflict with the wishes of an individual or of groups of service users who actually want or expect services or tasks to be carried out for them. From a review of this body of literature it can be deduced that participation increases feelings of control for the patient and this in itself is worthwhile and can lead to improved outcome (Brearley, 1990). However, these feelings of control may be illusory because an individual may be unable to actively exert control in reality because of overbearing social factors. Therefore it is argued that studies (Auerbach *et al.*, 1976) showing the importance of assessing individuals' perceptions of locus of control in order to predict whether they would be suited to participation in care are possibly meaningless in practice. It also serves as a reminder of the role played by the public, by wider society, in determining the experiences of older people. Older people were aware of the way that they could be 'marginalised' by society and identified closer social and community integration as a key outcome of health and social care services. These findings reinforce suggestions that greater attention should be given by health professionals involved in the care of people with the condition to closer co-operation with social care professionals (Qureshi, 1991), whilst acknowledging that these issues are only partially 'health' related.

### **The private accounts**

In the private accounts, any notion of simplicity is swept aside by a range of psychological, emotional, social and contextual influences. In these accounts, how older people conceptualise outcome, emerges out of, and is embedded within, the context of their life experiences, and the daily routines and events through which, and by which, their relationship with the world around them is maintained. These accounts embroider the complexities of everyday life, and



reveal the contradictions, the alternatives, or indeed lack of them, with which older people are faced when they are ill.

Within the private accounts, participants had different experiences of care, according to how decisions about care were made. For the purpose of analysis, participants were categorised into three groups: *empowered individuals*, *reluctant collaborators and dominated individuals*. These groups were formed as a result of examining participants' accounts on *how* and *why* certain topics or issues were raised or discussed. In this way, the *context* of participants' accounts remains core to the analysis, and ensures that the focus is not artificially skewed towards merely '*what*' was raised. This was to try and ensure that any discussion of outcome or outcomes identified mirrored the *form* of what people were saying as well as including the *content* (Long, 1996; Greenhalgh and Long, 1996).

Issues of power and control were central to these different experiences, to the dynamics of the accounts and to the public - private distinction. The way in which power and control were distributed within relationships was more important in determining the experience of care, than the number and range of activities undertaken on the participants' behalf. Within these two broad headings, then, the continuity and integrity of the private accounts is maintained by analysing the similarities and differences between the different groups, under three sub-headings. These are: relationships with 'significant others'; negotiating control; decisions about care, (including the role of health and social services). Given that many of the domains identified as important by older people were not simply *health* outcomes we have to value these relationships and experiences which shaped the person and had been developing over a long period of time. Illness and disability and the provision of care were part of their everyday experiences and circumstances and were reflected within an established balance of power.



Physical illness could substantially change the nature of these relationships and the balance of control. But this also is a *process* and this is discussed in the accounts. On the basis of decision-making, then, a typology of relationships presented in this thesis was developed. The typology of participants also provides a basis for understanding how older people in some circumstances may seek to control the behaviour of others, and how the activity and identity of care are bound together.

The limitations of this typology are recognised. Firstly, given the dynamic nature of relationships, it must be recognised that the balance of control within relationships may alter over time. Hence, while the typology may describe a *range* of relationships, the balance of power within one relationship may change overtime, and within it, the position of the relationship within the typology.

Secondly, classification is based on the views of only one party in the relationship. This may foster a polarised view about decision-making which might have been challenged had others involved been interviewed. Thirdly, although participants were interviewed several times and were theoretically sampled, the fact remains that only a small number were interviewed.

As previously suggested the typology developed in this thesis, classifies experiences and relationships according to the balance of power and control in the relationship. *Negotiated relationships* were those in which power and control were, by mutual agreement, shared. Where power and control resided with another person or persons, the relationship was defined as *dominated*. In other cases (*reluctant collaborators*), relationships appeared to be in a state of transition. In these relationships, the established balance of control was contested, and it was hard to say how the issue of control was going to be resolved. These cases were primarily classified according to the balances of control from which they were beginning to deviate.

### ***Empowered individuals***

Where participants felt they were in control, it was usual that this sense of control was a continuation of that experienced throughout life. This was a group of participants who felt largely in control of their lives. They seemed to dominate those around them, especially their daughters who seemed to provide much informal care. One daughter of a participant suggested that she believed her mother was using dependency as a way of ensuring receipt of what she felt she deserved or was entitled to.

Symmetrical relationships were those in which, from the participants point of view, decisions relating to care were equal. Decisions about care were reached through negotiation within a mutually supportive atmosphere. However, there were signs that this status quo could alter, as it was only in relation to the participants health that 'significant others' would act without the knowledge or consent of the participant.

These mutually supportive relationships which these participants enjoyed with friends and relatives succeeded through shared values and a shared understanding of the meaning of independence to the individual. Interestingly in these cases, the participant and their family both had separate commitments, and each encouraged friends and relatives not to see them as dependent, either as a sole source of social contact or help. Many other people were actively involved in their lives. Within this context, neither disability nor frailty translated into dependency.

### ***Dominated individuals and reluctant collaborators***

In this study, asymmetrical relationships (those in which one person was in overall control of decisions relating to care) were found to be the most common type of relationship. Within this group of relationships, the experience of

caregiving varied according to the responses of the person in the 'less powerful position' responses varied from active resistance to absolute and passive compliance. Participants in this group felt that their lives were intruded upon, that they were manipulated and felt coerced into accepting what others provided by the perceived threat of the consequences should they 'rock the boat'.

Interestingly, contrary to definitions of dependency with powerlessness, these relationships highlighted the ways in which some participants could be 'powerful' and dependent, and others could be independent (physically, if not psychologically) and powerless. In part, participants were able to define themselves as dependent because they had established a position of power which others 'accepted'. With the onset of chronic illness, it was possible to see how over time, a person's range of options narrowed, and the scope for changing the balance of power also diminished.

Financial and structural dependence on the state, meant that participants could not easily walk away from stressful situations, as they perceived there were few alternatives. However, even those participants who were felt to have power and control only had it as long as others around them were willing to tolerate it, as evidence by the participant who's daughter was increasingly making decisions such as insisting on an appointment for a hearing aid.

### **The significance of the public and the private accounts**

Taken together, the public and the private accounts of care outlined in this thesis begin to identify the complexities and the context of understanding how older people conceptualise outcome. They separate out the influence of wider social processes and normative beliefs, which may originate outside experience, from the more particular situational, psychological and family influences. This separation may be the product of the interview situation, a way of managing the



release of personal information. As such the public accounts reflect the prevailing moral context within which the private accounts take place.

The public accounts incorporate notions of reciprocity, justice and conscience as ways of describing more generally the context in which people operate. In doing so, these accounts taken alone gloss over the personal tensions and contradictions and reveal the profound embedding of ideology and interpersonal relations. These public accounts give us important insight into how older people present themselves in an interview situation, and this may be significant for understanding the responses people give to questions about their quality of life and outcome. If the public accounts were to be believed as 'reality', then paternalistic approaches to outcome measurement could be justified.

However, in the private accounts, a persons 'real' feelings emerge, as part of a developing predicament, rather than just a matter of individual temperament or moral disposition. These accounts show how choices and decisions are made over the lifecycle in response to a wide range of situations provide the foundations for understanding the personal 'inevitability' of care described in the public accounts.

The identification of public and private accounts of care and the diversity of relationships among older people, have implications for both the study of outcome and for service delivery. The relationship between the public and private accounts illustrate how explanations that older people give draw on the structural, situational, psychological and family influences over the life cycle within a broader social and cultural context. They show how conceptualising outcome is constructed and interpreted in different ways. The experience of care is affected by the dynamics of the relationships within the context of a persons own life, and the alternative courses of action.

The key theme to stress, however, was just how fluid and dynamic this process of change really is. It is well illustrated from models of chronic illness how people adjust and cope with chronic illness. What is important to stress from this study is that these chronic illnesses were incorporated into peoples lives, as another factor over the life cycle. The process of adaptation is dynamic. This concept of reflexivity is an important factor in the impact that even encouraging participants to *discuss* these issues in a research context can have. By getting people to think through, conceptualise and articulate their views and beliefs, we as researchers have to accept that we may be a core part of the process of changing an individuals expectations, the judgements they make and the meaning their circumstances have for them, and this may present particular ethical, moral and methodological challenges to how we manage this. Future approaches to person-centred outcome measures must consider how they can incorporate the huge variations in values and perceptions and rates of adaptation.

## **Outcome assessment within the policy context**

The use of outcome measures in the evaluation of health and social care services is increasingly stressed and has been embraced in legislation on health and social care in the 1990's. The NHS and Community Care Act (1990) proposes that individual professional assessments of need are holistic and document the full range of a persons needs through the care management process. At first glance, it would seem possible that methods for identifying and assessing the dynamics of relationships and circumstances could be developed within the framework of the recent legislation. However, a more detailed examination of the NHS and Community Care Act (1990), and it's accompanying guidance, highlights contradictions, tensions and gaps, which in turn, raise questions about the extent to which the position of some older people will



change. Leaving aside the broader policy questions concerning resources and inter-professional and inter-agency working, the future of service provision for older people will also depend on who carries out the assessments, who is assessed, and the interventions that they are assessed for.

In this study, it was clear that at any one time, where participants lived with others or lived alone, it would be difficult to determine who should have been assessed. In several cases, participants felt that their needs and wishes conflicted with others, be they spouses, family or friends. These relationships can be glossed over if assessments focus on the individual alone, ignoring the intense dynamics created in some families caring for frail older people (Stevenson, 1980).

According to the White paper, *Caring for People* one of the four components of community care is the provision of services that concentrate on those with the greatest needs. It would seem that only those people defined as having 'the greatest needs' will actually be assessed for services. As Chapter 3 suggests, resource allocation is budget controlled rather than demand led. This may mean that in providing service interventions for older people, they will continue to centre on *inability to cope*, rather than on establishing partnerships aimed at supporting and sustaining older people.

### ***Who carries out assessments?***

Who carries out the assessment will have important implications for the nature of assessment and the types of services that are offered, and the outcomes that are identified. Professional ideologies play an important role in determining how people are treated, where resources are allocated and to whom (Dalley, 1989). Health professionals who adopt a medical model of health and illnesses and positivist approaches to outcome measurement, may be predisposed to focus on



treatment and care in medical settings, rather than looking for social forms of provision. On the other hand, social care professionals may tend to over-emphasise the importance of social integration, over recognition of the consequences of illness (Dalley, 1989).

A manager obviously operates within financial constraints, and can be simultaneously responsible for individual assessment, service planning, service buying, service rationing, accounting and quality control (Barker, 1994). The potential conflict between these roles may constrain health professionals' ability to perform a thorough, independent assessment of need, and 'need' may be defined in terms of the available budget. In theory, budgets have been given to practitioners to achieve the greatest flexibility and choice for 'users' and 'carers', but there may be tensions between these two positions.

Health and social care professionals need to understand which accounts of care (public or private) they receive when they intervene. They need to understand the broader context of a person's life; their relationships and the dynamics within those relationships, as different combinations of service intervention might be appropriate. In some cases counselling, for example, maybe more appropriate than help with physical tasks. Focusing on physical tasks of the individual alone, may gloss over the opportunity for partnerships in care and the recipient as part of a unit. Those people with a low sense of self worth, and who felt they were a burden to their family and society, seemed more likely to have few expectations of services, and few ideas about what outcome they might expect for themselves.

### **Are people equipped with the necessary skills to meaningfully engage in the process of identifying outcomes?**

Barriers to participation in identifying and defining outcomes reflect broader participation in health and social care. Participation does not just concern

involving patients, their family and friends in physical tasks. It also concerns professionals enabling people to take *control* of the decision-making process. It involves 'expert' professionals passing their knowledge and skills to people with a view to promoting their sense of well-being and health. Research has repeatedly shown that patients are not involved in their care and are excluded from the decision-making process in that they are not given enough information. An alternative explanation is that neither patients or health professionals have insight into exactly *how* people might come to be involved in their care. Unless health professionals understand and value lay participation it will not be integrated. For health professionals to claim to be positive about involving patients is not enough since paying token lip service to the concept will fail to empower people to become more involved in their care. Increasingly, there is evidence that some individuals do not actually want to participate in care and may perceive it to be an added burden. It could be that people do not feel positive about participating in care because they did not fully appreciate what it means or because they were not being offered it in an appropriate manner. Likewise, people may not wish to participate in defining outcomes for health and social care.

May (May, 1992) suggests that patients may not see themselves as active, collaborative, partners in care or as experts in their own health. The data from this study supports these findings. However, other participants had a clear idea of what they wanted from health and social care services but were frustrated by the inflexibility of institutional structures and their lack of opportunity or ability to articulate these views.

When considering greater involvement of individuals in planning and in evaluating their health-care, then, the evidence is conflicting and inconclusive. This research tries to explore the relationship between older people's understanding of the concept and their acceptance of it in reality. It may be that

we need professional resocialisation to be able to facilitate the concept and also a re-education of the public to reorientate their expectations of health care.

Lack of communication between 'users' and 'carers' and health professionals is also a major factor. Health professionals may lack the necessary skills to offer holistic care. Health professionals may not always feel comfortable listening to 'users', helping them to come to term with their situations and deciding what is best for them. Poor communication between health professionals and people has been the greatest complaint to the NHS for decades. If health professionals are unable to communicate with 'users' and explore issues from a personal perspective, it is not surprising they appear to lack the skills to offer participation in care and in their approaches to person-centred outcomes. Health professionals also appear to find it difficult to assess plan, implement and evaluate individual care for individuals. It is perhaps unsurprising, then, that older people find these concepts difficult. Similarly, empowerment is not an easy concept to work into a system dominated by health professionals and bureaucracy. Roberts and Krause (1990) argue that if 'self care' is to be regarded as a mechanism for empowering people, the process of fostering control and encouraging people to take greater responsibility should be deliberate because this is difficult in settings dominated by the medical model. Health care professionals often lack training in sharing control and power. In both the private and public accounts, health and social care was often grouped together by participants as 'care', and it was difficult at times to distinguish which sector they were talking about. Similarly, they talked of 'they', and again it was difficult to discern if they were referring to health or social care professionals. Issues surrounding social integration were identified as key outcomes. Participants generally could identify what was important to them. However, making the distinction between need and service and outcome was more difficult.



They found it difficult to think in abstract terms and preferred to focus on 'present reality'. Another problem was that they found it very difficult to think of alternative services to what they knew already existed.

For true participation in care to become more than social rhetoric, a radical change is needed. Policy makers must be clear about whether participation in care is to be founded on humanistic or bureaucratic cost effectiveness. It would appear that unless health professionals share common values and principles of participation with each other and with people and policy makers, the radical changes needed will not be achieved. Until these changes are facilitated participation of older people in the identification and method of assessment of outcomes is unlikely.

### **Finale: changing the way we assess outcome**

This thesis has examined the perceptions and attitudes of older people towards greater involvement in care and in identifying and measuring process and outcome. It has shown that this normative approach to outcome measurement for older people is inappropriate because of the impact of 'structured dependency', particularly institutionalised ageism, on older people's abilities to participate in every day life and particularly to participate in the health and social care system. In the way we assess outcome, changes must be made at both the policy and methodological levels. Changing society's attitudes towards older people, although desirable, is, however, both idealistic and difficult. But, changes at the level of health and social care to tackle institutionalised ageism must be made. Until this is done, it presents a major barrier to greater participation in care and in turn meaningful involvement of older people in identifying and evaluating process and outcomes of care.

The diversity of views, perceptions, experiences and values militates against normative approaches to measuring outcome. It has been illustrated that older people are able to identify the *domains* which are important to their quality of life, but the data from this study suggests that unless these domains identified are contextualised within specific circumstances, then *interpretation* of any change within these domains is limited or hindered.

A focus on collecting outcome data draws attention away from evaluation of effectiveness and does not take account of low expectations or a lack of information. Therefore, at a methodological level, attention on *process* is as important for this group as outcome. We need to involve both quantitative and qualitative data collection methods in the assessment of process and outcome. Qualitative methods can be used to understand what is going on within a service or intervention, which is as important as quality of life outcomes.

An alternative theoretical perspective to process and outcome starts from the premise that it is the *meaning* that an individual attaches to an event or a series of events that is significant. Only that individual can articulate the subjective experience, in line with their own personal beliefs, views and experiences, contextualised in their own social world and circumstances. Only they can say what they consider to be a 'normal range of experience', and theoretically, only *they* can say how they are effected. In assessment of process and outcomes, best practice should ensure that all outcome measures are grounded in the *private* views of older people. Since not all older people have private views, we must focus on those older people who are more empowered. Further work needs to be done on how to get at their views. Measures constructed based on their views will be better than ones based on the views of professionals. Professionals must develop a much broader understanding of the meaning of the term person-centred.

Thus, for the future, a pragmatic approach to the measurement of process and outcome will be necessary. This should ensure that all outcome measures used in evaluation meet the criteria identified by Fitzpatrick *et al.* (Fitzpatrick *et al.* 1998), i.e. appropriateness, acceptability, interpretability, reliability, validity, responsiveness and feasibility. In the creation of any new outcome measures, attempts to capture the private views of empowered older people should be achieved through participation using qualitative research methods. Until we find ways of empowering older people to articulate *private* views, the modification of current methods to outcome evaluation will not be truly person-centred.



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## Appendix 1 Information Sheet

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### What is the purpose of this research?

The purpose of this research is to develop approaches to outcome measurement which are acceptable and useful to people like yourself at the day hospital, and their carers, and also to hospital staff.

### What are person centred outcome measures?

- Outcome measures are an important way of helping hospital staff to assess the benefits of various services/ treatments that they provide for people.
- A person centred outcome measure is one which actively involves the person, and their carers, in identifying their priorities for rehabilitation. This is with the view that if the person and their carer actively participate in the care process this may help treatment and/or services to be more relevant to each individual's needs.

### How will persons be involved in the study?

All new people at the day hospital will be invited to take part in the study. If you agree to take part in the study, we will then arrange a convenient time to talk with you about some issues which are important to help us. We will not be specifically interviewing anyone else at this stage, although if you have someone you would like to be with you when we come and talk to you, they are welcome to participate in the discussions. The interview will be very informal and may be in your own home, if this is convenient to you, or at the day hospital. Each discussion will last for approximately one hour. We appreciate you giving your time to participate in this research and your contribution will be valuable. But, you are under no obligation to take part and can withdraw at any time if you wish.

### Please note that:

- this study is a separate research project based at the University of Newcastle and will not effect the care you receive at the day hospital, or any other treatment / services you receive, in any way.
- the information you give us will be completely confidential and will not be discussed with the day hospital staff.

*I hope this information sheet has answered some of your questions about the study. If you would like further information, please contact me at any time at the address below, or telephone me. My telephone number is 0191 222 7252.*

**Lynne Corner, Research Associate**

**Centre for Health Services Research**  
University of Newcastle upon Tyne  
21 Claremont Place  
Newcastle upon Tyne. NE2 4AA

Telephone                    0191 222 7252  
Fax                            0191 222 6043

**Consent form**

**DEVELOPING PERSON CENTRED OUTCOME MEASURES**

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The objectives of the study above i.e. the development of a person centred outcome measure, have been explained to me and I have no objections to a member of the project team of the above study interviewing me or having access to any health records concerning me. Nor do I object to an approach being made either to staff or one of my informal carers.

Name ..... Signature .....

Consent obtained by ..... Date .....

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**Verbal consent witnessed by:**

Name ..... Signature .....

Relationship to person ..... Date .....

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**Consent given on behalf of the above person:**

Name ..... Signature .....

Relationship to person ..... Date .....



## **Appendix 2 Vignettes of focus interview participants**

All participants are referred to by pseudonyms throughout this thesis. In some places, details of participant's lives have been changed in order to preserve confidentiality. In these cases only minor changes have been made in order not to detract from the analysis or distort the participants identify in any way.

### **Empowered individuals**

#### **Mrs Bradley (30)**

Mrs Bradley talked animatedly and was a very enthusiastic person. She lived in a two storey house, decorated in strong colours. One wall of her lounge was covered in various family portraits and photographs and magazines and newspapers were piled high on a coffee table in the centre of the lounge. She had worked for an accountant as a secretary before she retired. Now 79, she lived alone following the death of her husband. Her two daughters lived locally and visited regularly with grandchildren.

#### **Mrs Brearley (1)**

Mrs Brearley asked to be interviewed in her kitchen, where she clearly spent most of her time. The kitchen was painted bright yellow and had french doors leading out into a small back yard which was painted white and had lots of pots with a variety of plants and fruit bushes in them. Mrs Brearley and her husband had moved there when her husband became unable to manage stairs at their other house. They had had the original wall and window knocked out to create the french windows, so the room was light and airy and his wheelchair could be easily manoeuvred. Mrs Brearley was 84. Her daughter visited regularly.

#### **Mrs Brown (28)**

Mrs Brown was widowed two years ago. She lived in her own house, with her daughter, Vera, her son in law, David, and two grandchildren. They had moved in with her six months ago. This arrangement seemed to suit everyone. Mrs Brown had previously lived with her other daughter, Pam, but this arrangement had not worked out. She described how she was left on her own for long periods of time each day, in an area where she had no friends, and subsequently began 'to go downhill'. She had put on a great deal of weight over the last year or so, and now was largely immobile and so spent most days sitting in her chair overlooking the back garden. She had just turned 79. Very amiable and friendly, she had been a housewife until her husband retired from his job as a builder for a large local firm.

#### **Mrs Cresswell (5)**

Mrs Cresswell and her husband were a very dour couple in their early sixties. They lived in a large bungalow surrounded by lawns and fields. They had spent over a year looking for somewhere suitable for their retirement and spent a lot of money on decorating and gardening. Mrs Cresswell's husband seemed very dominant and sat in

on the interviews with his wife. Mrs Cresswell had become ill suddenly after a left sided stroke. Several months after the stroke she had still not recovered the use of her left arm and her muscle paralysis had become much worse. Mr Cresswell washed and fed his wife, frequently turning her and rubbing pressure areas and encouraging her to undertake a rigorous routine of exercises recommended by the physiotherapist at the day hospital.

### **Mrs Dawson (43)**

This participant was 76. She had only recently returned home following a hospital stay after her heart attack - her third in as many years. She came across as being very positive and was looking forward to getting back to routine. She felt that this was the only context to really assess her progress and to see what the long term outcome for her would be when she was in her own familiar setting and therefore she could judge on what she used to be able to do. She had been widowed for just over a year and lived alone. Before retiring, she was a school administrator and was particularly articulate and opinionated.

### **Mrs Fitzgerald (10)**

Mrs Fitzgerald lived with husband, Derek, and had three sons and a daughter, all living locally, and grandchildren visited regularly. She was had recently been discharged from hospital following a hip fracture. She now attended the day hospital twice a week for rehabilitation, mainly physiotherapy. She was very positive about future, mainly she felt because she was confident of loving family support, whatever the outcome. She seemed placid and relaxed. Derek had been a piano tuner, and there were three pianos in the lounge. Mrs Fitzgerald was 81. She had not worked since having children, but had been a shop assistant before this.

### **Mrs Gaynor (44)**

Mrs Gaynor was currently attending the day hospital, but prior to this she had not been out of the house for two years. A widow for fifteen years, she lived in a quiet street in a terraced house, although she only lived in the downstairs. Her son lived in Canada, and although they spoke on the phone, he did not visit regularly. The oldest participant at 92 she was a slight woman, very slender and about five foot, and walked with a slight stoop. She enjoyed reading but her eyesight had deteriorated so that she was unable to read for long periods of time. Before she retired, Mrs Gaynor had worked in a material shop, her husband had worked for ICI.

### **Mrs Harriman (24)**

She had lived with her daughter, Moira, for some years. Widowed at thirty five she had run a fish and chip shop with her daughter's help. She was now 83. A large woman in stature, who smiled little, Mrs Harriman appeared to dominate the relationship and throughout the interview, frequently banged on the wall with her walking stick to attract her daughter's attention and tersely gave orders to her.



### **Mrs Hatfield (45)**

Mrs Hatfield's daughter provided most assistance for her, and did all her shopping and cleaning for her, although Mrs Hatfield insisted on preparing her own meals. She lived alone in sheltered accommodation. She was an avid reader, and the hallway was lined with bookshelves and books. Her husband had been a painter and she had kept his books for him when he was working. She had been very dizzy over the last months and had fallen several times, but had avoided serious injury. However, these falls had dented her confidence and she said she was nervous about leaving the house now, even when with her daughter. She had just celebrated her 84th birthday two days before the interview.

### **Mrs Johnson (29)**

Mrs Johnson was a very cheery woman, who talked animatedly, throughout the discussions. She had been dependent on insulin injections to control her diabetes since she was a young woman. Over the years, the diabetes had left her with several side-effects, including poor sight. Her daughter lived two miles away and came several times each day to give Mrs Johnson injections and help her to monitor her insulin levels. Mrs Johnson was in her early seventies. She looked small and frail, but talked with great energy. She had had a stroke which limited her mobility and her movement in her hands. A constant stream of visitors came in and out of the house during the interview. Mrs Johnson lived in a semi-detached house which had a welcoming cluttered feel to it.

### **Mr Kapper (18)**

Mr Kapper leaned forward throughout the interviews and had an air of intense concentration. He was articulate in voicing his views and interested in the purpose of the study. He was smartly dressed in a suit for the interview. He had suffered a stroke and also had very bad asthma, which necessitated him breathing from an inhaler during the interview. He had worked for a large bank and had moved around the country, only retiring to the area to be near his family. His wife was currently in a long-stay hospital, so he lived alone. He was 84.

### **Mrs Lorrimer (22)**

Mrs Lorrimer had lived all her life in the south of England, but when her husband had retired, they had moved North to be near their daughter and her family. However, shortly after they had moved, her husband died, and Mrs Lorrimer felt unceasingly unsettled, eventually buying a house further South again. However, she became increasingly lonely and eventually had moved in with her daughter. Their relationship seemed tense. Mrs Lorrimer had fallen some months ago and now spent most days in bed, while her daughter looked after her. She was a tall woman, with dark hair who was 75 years old. Her husband and her had owned their own plumbing business.

### **Mr Lynch (46)**

Mr Lynch was a tall man in his early seventies. He had been taken into hospital after collapsing at a family birthday party. His stroke had affected his speech and he found it difficult to communicate. He lived with his wife and a daughter and son visited regularly with grandchildren. He also cared for his wife, who had also had a stroke. They both



contributed to the discussions. He had been in the army for a time, and wore a navy blazer with a badge and a tie from his old regiment, and often talked in terms of routine and order.

### **Mrs Royale (11)**

Mrs Royale lived alone, but close to her daughter Pam who provided much of her care and visited each day after work. She had had two strokes, the most recent one three months ago. She was enthusiastic about taking part in the discussions and asked for a copy of the report to be sent to her at a later stage. She increasingly relied on her daughter to visit daily. She had worked at a local clothing factory for thirty years before she retired, ten years ago, at the age of 65.

### **Mr Henry (39)**

Mr Henry had been a miner for over forty years. He was now 87. A few years before he retired, his foot was crushed in an accident at work and he now walked with a pronounced limp, which was aggravated by arthritis. A keen follower of sport, he spent most days watching the satellite channels for sport, and was particularly fond of cricket. He lived with his wife, and despite advanced heart failure which left him tired, and unable to walk more than a few metres at a time, he felt that he enjoyed life to the full.

### **Mr Mason (47)**

Mr Mason was a small man with round glasses who smiled a lot. He was very keen to help with the study in any way he could, and offered to help with and typing that needed to be done. He had worked as a surveyor and had recently taken a computer course and was designing his own house on his new computer. He had cancer of the prostate and arthritis in his knees, but said he felt reasonably healthy. He lived with his wife, in a bungalow on the outskirts of town.

## **Reluctant collaborators**

### **Mrs Blackwell (20)**

Mrs Blackwell is in her late sixties and 'had gone very thin' since being ill. She lives with her husband who is in his late seventies. She had been taken ill since a stroke some months ago and was currently altering the house, by moving rugs and furniture, so that she could move around with a walking frame. She said she was resigned to a life indoors following her stroke, but hoped she would be able to go to her granddaughters 10<sup>th</sup> birthday party the following week at a local sports centre. She was clearly in some pain throughout the interview and could not sit for long periods of time in the same position.

### **Mrs Jones (14)**

Mrs Jones was 85 and suffered from severe arthritis, in her hands, knees and spine. She was clearly in a great deal of pain. She remained in bed most days and a home help from social services came in once a day to help get her a meal at lunchtime. Mrs

Jones had been the cook in a canteen at the local primary school for ten years, which she had really enjoyed. She was critical of the unimaginative and inflexible way she felt services were offered to her. She was tearful throughout the interviews and was clearly in a great deal of pain. She still enjoyed cooking when she got the opportunity. Her bookshelves were full of well-thumbed recipe books and one was open on a table at the time of the interview; Mrs Jones said she enjoyed leafing through them and preferred these to reading novels as she could not concentrate and see as well as she used to.

### **Mrs Kennedy (13)**

Mrs Kennedy lived in a small one-bedroom ground floor flat on the edge of a large council run estate, which was known locally as a 'problem' area. On approaching the estate, many of the houses had boarded up windows and were derelict and deserted. Mrs Kennedy had moved there from another part of town some months ago as she felt that the stairs in her house were too steep for her as she was very breathless as a result of heart failure and had fallen several times. She felt very unhappy, depressed and isolated and was considering leaving the area to live near her daughter in Kent. She was 75.

### **Mr Bentley (15)**

A major stroke three years ago which had left Mr Bentley with limited movement of his left arm. His speech was slightly slurred and he had developed a stutter since the stroke, which embarrassed him. He was a tall man, very smartly dressed with white curly hair and a very intent manner. He seemed tense at first and very uncertain, but then relaxed and was increasingly confident in expressing his views. He lived alone in rented accommodation and was 79.

### **Mrs Barker (19)**

Mrs Brandon was a small stout woman with black hair and large red glasses. She lived alone: her husband died five years ago. She was 86 and was attending the day hospital as she had fallen several times in the last six months and was receiving physiotherapy for arthritis in her spine and knees. A keen churchgoer all her life, she now attended infrequently as she could no longer walk to church alone and felt that neighbours were reluctant to commit themselves to giving her a lift on a regular basis. The fact that she was unable to go out on a regular basis was getting her down and she said she was feeling very depressed.

### **Mrs Clare (3)**

Mrs Clare is a large woman in her late sixties. She spends most of the day confined to bed, or sitting in an 'orthopaedic' chair beside her bed. Her time is spent reading, listening to the radio or watching the television. She has two daughters and a son. One of the daughters lives nearby and there is a steady stream of visitors to the house. Her husband and her sold their large family home to move into a purpose built flat to make it easier for Mrs Clare to move around as due to severe arthritis, her mobility is limited. They both have occupational pensions and in addition receive an income from investments.



## **Mrs Crawford (31)**

Mrs Crawford is 86. She lives alone in the centre of the town in sheltered accommodation. She was dressed for the interview in a matching tweed skirt and jumper and wore a pale pink lipstick. The house was very tidy and smelled of wax polish. She had baked cakes before the interview. Her day hospital notes suggested that she was in the early stages of dementia and her family were very protective of her. She said that she had become forgetful, however, she had remembered that she was being interviewed on two separate occasions, and had laid a table with tea and cakes. She was very worried about the future, seemed extremely depressed, and on each visit I felt a sense of her extreme loneliness.

## **Mr Benfield (12)**

A foreman at ICI, he had only retired four years ago and still kept in touch with many of his work colleagues. He lived with his wife, who worked as a cleaner at local offices. He was attending the day hospital for tests as he had been suffering from severe headaches and blurred vision. He was very quiet and calm in the interviews and not very talkative.

## **Mrs Chalmers (9)**

Mrs Chalmers was very talkative. She lived alone in her own home. She had worked as a legal secretary for thirty years, in the same firm of local solicitors. She was keen to remain independent and looked forward to going shopping every week as it was her only opportunity to 'get out'. Her television was turned up very loudly throughout the interview as she was very deaf. Her daughter was insisting that she went to get a hearing aid, but Mrs Chalmer's didn't see why she needed one.

## **Mr Jenkins (4)**

Mr Jenkins lived in a house which was cluttered with various pieces of furniture. He had been a cabinet maker and the house was full of 'special cases' that he couldn't bring himself to sell or throw away. He was widowed and lived alone with no family nearby. He was at the day hospital for physiotherapy following a hip replacement, but felt that he was remarkably agile for a 'man of 76'.

## **Mr Palmer (16)**

Mr Palmer was very reserved and seemed quite shy. But very polite. He lived with his wife and their son, who was recently divorced. Following a stroke and a heart attack in the same month, he was clearly very frail, but said that just two months ago he had been happily pottering in the garden. He felt that they may have to move if he did not improve as the garden was too big for his wife to manage. He was 72.

## **Mrs Mona (7)**

Mrs Mona was very depressed at the time of the interview. She said she felt lonely and isolated, and she still had not adjusted to retirement. She had taken local boys on as lodgers who were training at a local football club. She lived in a large rambling Victorian house, set about thirty metres off the main road. She had been born in Spain, but



married a local man and had lived in the UK for forty five years. She was now 74. Her family lived nearby and were encouraging her to go to a day centre but she did not want to go.

### **Mrs Patrick (2)**

Mrs Patrick was small and frail. She lived in sheltered accommodation, in a small bungalow. She had a slightly eccentric air which was exaggerated by her tendency to talk and mutter to herself. She wore a hat with an ostrich feather in it throughout the interview, while dressed in her night clothes. She was at the day hospital because she had oedema in her legs, but otherwise felt fit. She was 76.

### **Mrs Sutton (8)**

Mrs Sutton was considering moving into residential care. She seemed very positive that this was the right decision initially, but eventually, her 'public' voice was that she very much preferred to stay in her own home, but felt pressurised to move, as she knew her family were worried about her living alone. She said she felt very alone, despite the fact that her son and daughter lived locally and visited regularly. Her son cut her lawn and did some gardening for her, while her daughter helped with any cleaning. She was a thin woman, 84, with thick glasses, and very smartly dressed.

### **Mrs Taylor (6)**

Mrs Taylor was a very anxious and nervy person, and sat throughout the interviews tearing a tissue into small pieces, or wringing her hands. She was very thin and looked very tired with black rings under her eyes. She had had a TIA. She had been discharged from hospital four weeks ago and felt very tired, fed up and that the future was bleak. She was 84 and lived alone in a terraced house in the middle of town.

### **Mr Tilsey (17)**

She had been an active member of her community for over forty years; she had been president of the woman's guild and with her husband, had been members of the Rotary club. She was very proud of her achievements and felt sad that they had ended, and many friendships with it. She was widowed and had a daughter and son living nearby who visited regularly. Now 86, she had only recently retired from her role as chair of the woman's guild, and felt frustrated that she could no longer attend and missed the socialising very much.

## **Dominated individuals**

### **Mr Langton (41)**

Mr Langton was in his early seventies. On the first interview he was sitting in the lounge, on the second he was lying down on his bed. He lived with his wife in a small one bed-roomed ground floor council flat. Mrs Langton did everything for her husband: she lifted him, washed and dressed him, fed him, and wiped his nose when it was running. Mr Langton did not communicate well and was often monosyllabic in his

responses. He had had a stroke some years ago, from which he had almost fully recovered and was not receiving any treatment at the time of the interview.

### **Mr Reed (40)**

Mr Reed had had a stroke. He was very reluctant to participate in the interviews, and often answered in monosyllables. He said that he needed reassurance, had confidence in expert professionals, preferring to defer to professional opinion. He had been a workman at ICI all his working life and was now 75 years old. He lived alone, following the death of his wife sixteen years ago. He was very thin and wore a jumper which had food stains and holes down the front.

### **Mrs Bell (42)**

Mrs Bell is 87. She has respiratory problems and is unable to walk far. She lives alone and felt depressed and miserable. She was in tears for a large part of the interview and was clearly distressed. She lived alone and had been widowed for four years and was grieving. Her son lived down south, but a daughter lived locally. Her house was very untidy and there were several plates of uneaten food on the floor.

### **Mrs Black (38)**

Mrs Black had a chronic respiratory problem and severe arthritis in her hands and knees. Despite her difficulty breathing, both she and her husband smoked continuously throughout each interview, which occasionally sent them both into fits of coughing. Mrs Black is a quiet person, a tall slender woman with cropped white hair. She had her own room in the downstairs of the house, but was never left in the house alone. She was in her early seventies.

### **Mrs Luton (25)**

Mrs Luton spoke in a slow deliberate manner. She was very depressed and frequently said that she wanted to die. She lived alone in sheltered accommodation. A home help visited daily. She was 68.

### **Mr Geraint (36)**

Mr Geraint is a large rotund man in his middle sixties. He answered the door, breathing very hard from the exertion of moving around. His wife is in her early seventies. Mrs Geraint is a stout woman with arthritis. She sat in a tall, heavily padded chair opposite me throughout the interview with her husband. Both Mr and Mrs Geraint had faint traces of a South African accent as they had lived there for fifteen years and two of their daughters still lived in Johannesburg. Had they both not been in poor health they said they would have retired there, four years ago. Mr Geraint could walk slowly and painfully on his own with the aid of a walking frame. He could not however wash himself or carry out household activities. They had paid for adaptations to be made throughout the house to reduce dependence on each other and social services.

### **Mr Barry (37)**

Mr Barry is tall and slightly stooped in his early seventies, with a round face and bright white hair. They lived in a house crammed with antiques and old furniture. The house was set in extensive grounds which Mr Barry looked after with the help of a gardener who came once a week. He also had a wood working shed in the garden in which he continued to make furniture. Since his stroke, Mr Barry had been increasingly withdrawn and his wife said that he was much quieter than her had been and his personality and changed.

### **Mrs Alford (23)**

Married to Alf, Mrs Alford had angina attacks and was slightly deaf, but considered herself fit. Alf was very protective and dominated the first interview, and answered on Mrs Alford's behalf on several occasions. Her husband made all the decisions around the house, and did all the shopping and household chores. Their daughter visited daily. She was pale with a deeply lined forehead and a distracted manner. She was 75. They lived in a second floor flat, which had three rooms.

### **Mrs Mortimer (35)**

Mrs Mortimer appeared very tired and very frail. She had advanced heart failure and had great difficulty breathing. She was in her late 60's. She walked with the aid of a walking frame and had had to sell most of her furniture in order to ensure that she could move around her small flat. A home-help did all her shopping and cleaning. She said she was too weary to talk much and the interview only lasted an hour. Mrs Mortimer declined to be interviewed a second time, saying she felt too tired and didn't feel she had anything to say.

### **Mrs Shannon (33)**

Mrs Shannon had phlebitis in her legs. She said that she occasionally 'came over all funny' and felt confused. She lived with her husband and social services and a district nurse visited daily. She seemed preoccupied with her illness and talked of little else. A large woman with curly hair she was very friendly and hospitable.

### **Mrs Carter (26)**

Mrs Carter had had a stroke. Her husband organised a strict regime of activities for her. She had little to say but seemed very content to be interviewed. She was dressed completely in blue and had matching glasses for whatever outfit she chose. She was interviewed with her husband who answered for her much of the time.